

PROVIDING QUALITY CARE

**Exploring contextual influences and ethical
issues inherent in the delivery of quality care
for people with dementia**

By

Pauline O'Connor

A thesis submitted in fulfilment of the requirements for the degree of

Doctor of Philosophy

**University of Edinburgh
School of Social and Political Studies**

2005



TABLE OF CONTENTS

| | |
|--|-------------|
| LIST OF TABLES | viii |
| GLOSSARY | 9 |
| ABSTRACT | 12 |
| STATEMENT OF ORIGINALITY..... | 14 |
| ACKNOWLEDGEMENT | 15 |
| PROLOGUE: Roots of the Concerns Informing this Research..... | 16 |
| 1 Susan's Story | 16 |
| 2 Issues Emerging from Susan's Story..... | 19 |
| 3 The Policy Context | 22 |
| 4 Changing Perceptions of Dementia | 25 |
| 5 Caregivers - needs and competencies | 26 |
| CHAPTER 1: Demographic, Funding & Service Trends in Care Delivery28 | |
| 1.1 Introduction..... | 28 |
| 1.2 Increasing Longevity - a burden or a blessing? | 28 |
| 1.3 Population Projections and Prevalence Rates of Dementia in the UK | 30 |
| 1.4 Prevalence of Dementia in Scotland..... | 32 |
| 1.5 Living Circumstances of People with Dementia - Levels of Dependency | 36 |
| 1.6 Care Environments | 40 |
| 1.7 Funding Long Term Care | 43 |
| 1.8 Quality Care: Current Standards and Problems | 45 |
| 1.9 Providing Quality Care – Promoting Standards through Policy Changes | 46 |
| 1.10 Managing the Care Needs of Patients with Severe Dementia. | 49 |
| 1.11 Conclusion | 50 |
| CHAPTER 2: Understanding Dementia..... | 52 |
| 2.1 Introduction..... | 52 |
| 2.2 Defining Dementia - A Medical Model Perspective..... | 53 |
| 2.3 The Medical Model is Problematic..... | 54 |

| | | |
|---|--|------------|
| 2.4 | Medical Practice and Ethical Responses..... | 58 |
| 2.4.1 | A Son's Request for Nondisclosure | 58 |
| 2.5 | Conflict between principles of biomedical ethics..... | 63 |
| 2.6 | Changing Perspectives on Dementia | 65 |
| 2.6.1 | The Psychosocial approach to Dementia..... | 65 |
| 2.6.2 | The Concept of 'Personhood'..... | 66 |
| 2.7 | Characteristics and Criticisms of Medical and Psychosocial Models..... | 68 |
| 2.8 | Re-Thinking Personhood and Person-Centred Care | 71 |
| 2.9 | Conclusion | 75 |
| CHAPTER 3: Understanding Nursing Care Practice | | 77 |
| 3.1 | Introduction..... | 77 |
| 3.2 | Quality of Life in Advanced Dementia..... | 79 |
| 3.3 | Quality of Life Components | 80 |
| 3.4 | Adopting a Palliative Approach..... | 82 |
| 3.5 | Understanding Nursing Care | 84 |
| 3.6 | Case History: The Reaction of Instinct and Experience | 85 |
| 3.6.1 | Shared Meanings..... | 86 |
| 3.6.2 | Sources of Carer Stress..... | 88 |
| 3.7 | The Practice of Caring | 89 |
| 3.8 | The Caring Professional..... | 92 |
| 3.8.1 | Learning To Pass a Nasogastric Tube. | 92 |
| 3.9 | The Patient's Perspective | 93 |
| 3.9.1 | 'Doing Things She Really Didn't Want To Do.' | 94 |
| 3.10 | Managing an Abusive Patient..... | 97 |
| 3.11 | An Ethic of Caring..... | 100 |
| 3.12 | Conclusion | 102 |
| CHAPTER 4: Research Design | | 103 |
| 4.1 | Introduction..... | 103 |
| 4.2 | Motives and Goals | 104 |
| 4.3 | Research Strategy | 105 |
| 4.4 | Selecting Study Site..... | 106 |
| 4.5 | Considering a Comparative Study | 107 |
| 4.6 | Selecting the Study Site | 109 |
| 4.7 | Staff Mix and Years of Experience on Karibu Ward..... | 112 |

| | | |
|---|---|------------|
| 4.8 | Methods of Inquiry | 114 |
| 4.8.1 | Observation | 114 |
| 4.8.2 | Semi-Structured Interviews/Conversations | 115 |
| 4.9 | Data Collection | 118 |
| 4.10 | Time Sampling..... | 119 |
| 4.11 | Theorising and Generalising..... | 120 |
| 4.12 | Recording Data | 122 |
| 4.13 | Data Analysis..... | 124 |
| 4.14 | Ethical and Relational Considerations..... | 125 |
| CHAPTER 5: Ward Layout, Furniture & Equipment..... | | 127 |
| 5.1 | Introduction..... | 127 |
| 5.2 | The Physical Environment..... | 127 |
| 5.3 | Key Characteristics | 129 |
| 5.4 | Layout and Furnishings | 130 |
| 5.5 | Shared Facilities..... | 132 |
| 5.6 | Lack of Space | 133 |
| 5.7 | Seating and Mobility Devices..... | 133 |
| 5.8 | Ambience and Orientation | 134 |
| 5.9 | The Staff Room..... | 135 |
| 5.10 | Summary..... | 136 |
| CHAPTER 6: Care Delivery on Karibu Ward: Practicalities & Priorities | | 138 |
| 6.1 | Introduction..... | 138 |
| 6.2 | Themes Identified | 138 |
| 6.3 | The Daily Rhythm of Ward Life..... | 140 |
| 6.3.1 | The morning shift | 140 |
| 6.3.2 | Afternoon Shift..... | 143 |
| 6.3.3 | Night Shift | 145 |
| 6.4 | The organisation of ward life and patient care..... | 145 |
| 6.5 | Themes Underpinning Care Delivery | 146 |
| 6.6 | Routinisation of Care | 147 |
| 6.7 | Prioritising Physical Care | 147 |
| 6.8 | Communication Issues..... | 148 |
| 6.9 | Environmental Influences..... | 149 |
| 6.10 | Managing Challenging Behaviour | 149 |

| | |
|---|------------|
| 6.11 Conclusion..... | 150 |
| CHAPTER 7: The Impact of Routine & Environmental Influences on Care Delivery | 152 |
| 7.1 Introduction..... | 152 |
| 7.2 Most People are 'Creatures of Habit'..... | 153 |
| 7.3 Ward Routines: The Morning Schedule | 154 |
| 7.4 Rationale Underpinning Ward Schedules..... | 156 |
| 7.5 Routine: A Coping Mechanism | 158 |
| 7.6 Resistance to Disruptive Routine Care Practices..... | 161 |
| 7.7 Environmental Influences..... | 163 |
| 7.8 The Relationship between Shared Space and Patient Behaviour..... | 164 |
| 7.9 Use and Availability of Appropriate Seating and Mobility Devices for Patients..... | 168 |
| 7.10 Staff Facilities..... | 169 |
| 7.11 Conclusion..... | 170 |
| CHAPTER 8: Prioritising Patient Care | 172 |
| 8.1 Introduction..... | 172 |
| 8.2 Specific Characteristics and Dependency Levels of Patients | 173 |
| 8.3 Prioritising Patient Needs | 174 |
| 8.4 Evidence of the Prevailing Influence of the Medical Model on the Management of Patient Care. | 176 |
| 8.5 Some Ethical Consequences of Current Practices for Patients..... | 178 |
| 8.6 Further Ethical Implications of a Medical Based Approach to Care | 180 |
| 8.7 Custodial Approach to Care..... | 182 |
| 8.7.1 Management of Patient Mealtimes | 182 |
| 8.7.2 Limited Patient-Carer Interaction..... | 184 |
| 8.8 Further Evidence of a Warehousing Approach to Care..... | 187 |
| 8.9 Conclusion | 189 |
| CHAPTER 9: How Carers Managed Psychosocial Aspects & Special Challenges in Care Delivery | 191 |
| 9.1 Introduction..... | 191 |
| 9.2 Therapeutic Encounters | 192 |
| 9.3 How Ineffective Communication Strategies Appeared To Have A Negative Effect On Care Outcomes..... | 194 |

| | | |
|--|---|------------|
| 9.4 | Assumptions About Care Practices..... | 197 |
| 9.5 | Meeting The Psychosocial Needs Of Patients | 200 |
| 9.6 | Other Aspects Of Psychosocial Care | 202 |
| 9.7 | The Care Management Of Patients With Challenging Behaviour..... | 205 |
| 9.7.1 | Patient Refuses Medication | 206 |
| 9.8 | Conclusion | 211 |
| CHAPTER 10: Quality Care & Carers' Job Satisfaction | | 213 |
| 10.1 | Introduction..... | 213 |
| 10.2 | Job Satisfaction and Quality Care..... | 213 |
| 10.3 | Carers' Perspectives | 215 |
| 10.3.1 | Nurse Assistants | 215 |
| 10.3.2 | Nurses..... | 218 |
| 10.4 | Leadership Styles and Staff Relations | 220 |
| 10.5 | Other Factors Influencing Carer Assistants' Attitudes to their Role | 223 |
| 10.6 | Perpetuating Inadequate Care Practices..... | 224 |
| 10.7 | Karibu Ward Perceived as the Cinderella of the Hospital Service. | 227 |
| 10.8 | Conclusion | 228 |
| CHAPTER 11: Summary of Study | | 230 |
| 11.1 | Summary of Findings | 231 |
| 11.1.1 | Routinised Care Issues | 231 |
| 11.1.2 | Therapeutic Aspects of Care | 235 |
| 11.2 | Recommendations..... | 237 |
| 11.2.1 | The Need to Define Care According to Patient Need | 238 |
| 11.2.2 | A Palliative Care Approach..... | 239 |
| 11.2.3 | Ongoing Training and Development of Staff..... | 240 |
| 11.2.4 | Carer-Patient Ratios..... | 242 |
| APPENDIX A: Courtesy Letter to Committee | | 244 |
| APPENDIX B: Letter of Response from Committee..... | | 245 |
| APPENDIX C: Introductory Statement..... | | 246 |
| APPENDIX D: Cheat Sheet..... | | 247 |
| APPENDIX E: Sample of How Major Themes Emerged..... | | 248 |

APPENDIX F: Karibu Ward: Semistructured Interview Format..... 250

REFERENCES 252

| | |
|---|-----|
| Glossary | 252 |
| Prologue: Roots of the Concerns Informing this Research | 252 |
| Chapter 1: Demographic, Funding & Service Trends in Care Delivery | 253 |
| Legislation | 257 |
| Chapter 2: Understanding Dementia | 257 |
| Chapter 3: Understanding Nursing Care Practice | 261 |
| Chapter 4: Research Design | 264 |
| Chapter 5: Ward Layout, Furniture & Equipment | 265 |
| Chapter 6: Care Delivery on Karibu Ward: Practicalities & Priorities | 266 |
| Chapter 7: The Impact of Routine & Environmental Influences on Care Delivery... | 267 |
| Chapter 8: Prioritising Patient Care | 268 |
| Chapter 9: How Carers Managed Psychosocial Aspects & Special Challenges in Care Delivery | 269 |
| Chapter 10: Quality Care & Carers' Job Satisfaction | 270 |
| Chapter 11: Summary of Study | 271 |

LIST OF TABLES

| | |
|---|-----|
| Table 1.1: Prevalence of Dementia in the Community (adapted from EURODEM data 1995)..... | 31 |
| Table 1.2: Age Specific Prevalence of Dementia (%) in the Elderly..... | 33 |
| Table 1.3: Number of people with dementia in Scotland according to age groups and gender | 34 |
| Table 1.4: Projected estimate of growth in the number of people with dementia in Scotland by age group..... | 35 |
| Table 1.5: Percentage of people with dementia by place of residence | 37 |
| Table 1.6: Anomalies in the balance of care data | 37 |
| Table 1.7: Percentage of people with dementia by place of residence and levels of dependency | 38 |
| Table 1.8: Percentage of people with dementia by place of residence and the types of assistance required more than once daily | 39 |
| Table 1.9: Environmental Review | 41 |
| Table 1.10: The balance of Community Care Expenditure for Older People | 43 |
| Table 2.1: The Standard Paradigm of Dementia Care | 56 |
| Table 2.2: Two cultures of dementia care..... | 69 |
| Table 4.1: Years of experience on Karibu Ward..... | 112 |
| Table 4.2: Demographic Characteristics of Karibu Ward..... | 112 |

GLOSSARY

The following terms are used throughout the thesis:

Carers Carers is a generic term used in this study to refer to the 6 trained nurses, 8 enrolled nurses, and 10 nurse assistants comprising the staff on Karibu ward. All carers were paid staff members and through the text the word staff or staff members are sometimes substituted for the term carers. When deemed necessary a distinction is made by the use of the more specific terms nurse, enrolled nurse and/or nurse assistant for the purpose of clarity.

Dementia without behaviour disturbance

Mild Residents being admitted for care as they are suffering from dementia with the following symptoms:- memory impairment; decline in orientation; beginning to need supervision in activities of daily living. (Lothain Health Board 1997)

Moderate Residents being admitted for care as they are suffering from dementia with the following symptoms:- more severe memory loss resulting in little effective memory; poor orientation, needing a lot of supervision in day to day matters; unable to take initiative in activities of daily living. (Lothain Health Board 1997)

Severe Residents being admitted for care as they are suffering from dementia with the following symptoms:-need for physical care predominates, little effective interaction with others. (Lothain Health Board 1997)

Dementia with behaviour disturbance

Residents being admitted for care as they are suffering from mild/moderate/severe dementia as defined above plus such associated symptoms as:- tendency to wander, mood disturbance, aggressiveness, disinhibited behaviour – which require specialist assessment and special expertise in management. (Lothain Health Board 1997)

| | |
|------------------------|--|
| Elderly | Elderly pertains to persons in late life and in the context of discussion in this paper recognises the fact that 'at postmortem, Alzheimer's disease appears to occur in about half the population of elderly people with dementia' (Holden & Woods 1995, p. 6). |
| Enrolled Nurse | A two-year trained nurse whose function in principle is to assist. (Davies 1995, p. 6) |
| Null Behaviour | A continuous lack of any observable behaviour or activity, otherwise known as 'doing nothing' and 'staring'. 'Null behaviour is likely to occur when residents do not have the opportunity to choose between privacy and socialization'. (Rader & Tornquist 1995, p. 70) |
| Nurse | A three year trained nurse who has a qualification as a registered General Nurse (RGN). (Davies 1995, p. 6) |
| Nurse Assistant | Is a non-nurse helper whose training consists of a six-week in-house Training program on basic nursing care practices. (Davies 1995, p. 111) |
| Palliative Care | Provision of care for people in the end stages of dementia or people with dementia dying of other causes in order to ensure that people with dementia die with dignity, without pain, and with as much comfort as possible. (Sheard & Cox 1998) |
| Patients | Refers to the 20 women living with severe dementia being cared for on Karibu ward. |
| Staff/Carers | This refers to registered nurses, enrolled nurses and nurse assistants. |
| SDU'S | Specialist dementia units. (Archibald 1997) In the US and UK a wide range of SDU's has been established. Some units simply provide a physical distancing/clustering of residents with dementia within a building whilst in other SDU's the specific needs of carers and patients have been taken into account in the design of the buildings. (Archibald 1997) |

Senility

'In the past, the syndrome of dementia was subdivided into a presenile and a senile type...younger 'presenile' patients (up to 65 years of age) may have been referred more often to neurologists for expert diagnosis and possible treatment...while the older 'senile' patients were seen as suffering from ordinary problems of old age...the result has been considerable vagueness in describing 'senile dementia' (Jacques & Jackson 2000, pp. 11-13).

Senility was generally understood to mean showing a loss of faculties associated with old age and was usually considered evident when older persons began to show signs of forgetfulness, confusion or frailty. In the past these behaviours were often considered 'just getting old' for which there was no specific treatment.

In more recent times however, in the interest of greater clarity the presenile/senile distinction has been dropped for the purpose of looking at dementia as a whole and examining its underlying diseases. (Jacques & Jackson 2000, p. 14) The word senility (instead of dementia) was used in the Prologue of the text since it more truly represented the time in which the story of Susan was set and perceptions of old age at the time.

Sufferers

To suffer, according to the Collins Dictionary (2002, p. 923) is to undergo or be subjected to physical and/or mental distress or to be badly affected by an illness. While acknowledging that 'political correctness' may suggest that we do not describe people with dementing illnesses as sufferers, or victims, afflicted with a debilitating disease, (Goldsmith 1998, p.2) accepting the convention of the use of the phrase 'people with dementia' as the only appropriate phrase is not necessarily an adequate way of reflecting some of the discussions in the literature, see (Holden & Woods 1995, pp. 3-11).

'Terminal'

Refers to patients who are 'bedfast, mute, dysphagic, intercurrent and infectious in terms of their care needs. (Volicer & Hurley 1998, p. xii)

ABSTRACT

This thesis is an exploratory study of the contextual influences and related ethical issues inherent in the process of caring for people with dementia. The findings of the study are based on the work and experiences of twenty-four carers who were observed and interviewed during the course of caring for twenty female patients living with severe dementia.

Based on a grounded theory approach to data collection the following five themes or aspects of care delivery emerged providing a focus for an in-depth analysis of how care was delivered:

- The management of care according to daily and weekly scheduled tasks
- The promotion of the physical needs of patients over other aspects of care
- Communication difficulties in patient-carer encounters
- Environmental issues relating to the location, layout and design of the study site
- The management of patients with challenging behaviour

The examination of each theme illuminated the nature and extent of contextual influences on care delivery, including staff morale. The findings of the study revealed that the overall approach to care had its roots in well established prescribed methods of nursing practice, which were sustained by three distinctly independent but related factors:

- Staff training
- Previous work experience
- Carers understanding of dementia.

These factors seemed to be foundational to issues identified of an ethical nature in terms of the management of aspects of patient care. The ethical concerns explored in the study were primarily associated with assumptions made by carers regarding the inability of the patients to make choices or express preference for example with respect to care and the management of their environment.

An exploration of the approach to care delivery revealed a dominance of the medical model in care delivery practices and in particular with regard to carers understanding of dementia. While the study recognises the fact that the medical or organic model of care including the use of drugs has undoubtedly enhanced the physical health and cognitive functioning of patients for some years, it recommends that carers become aware of existing and developing alternative philosophies and practices underpinning a new culture of dementia care. The study concludes that combining the essential elements of the organic

model with respect to diagnosis and medical treatment with an approach that is cognizant of a patient's history, biography and subjective expectations and experiences is likely to ensure the delivery of improved quality care based on a holistic approach.

STATEMENT OF ORIGINALITY

*Exploring contextual influences and ethical issues inherent in the delivery of quality care
for people with dementia*

Pauline O'Connor

The work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and to the best of my knowledge contains no material previously published or written by another person, except where due reference has been made in the text.

Pauline O'Connor

30th September 2005

ACKNOWLEDGEMENT

*I can no other answer make but thanks,
and thanks, and ever thanks*

-Twelfth Night

I would like to record my profound thanks to the Australian province of the Sisters of St John of God who financed me during my research and were my constant support and encouragement.

I would like to express my gratitude to my supervisors Mr. Richard Parry, Reader in Social Policy; Professor Kath Melia, Professor in Nursing Studies and Head of the School of Health in Social Policy and Dr Alex Robertson, Reader in Social Policy for their feedback, encouragement and support throughout the duration of the study. Special thanks to Alex for his supervision which was characterised by firm direction, timely advice and sustained guidance.

Helpful support and insightful comments on drafts of my work were received from Professor Ian Thompson. My thanks also go to Alison Thompson and Mary-Ann Branson who examined the thesis for slips in cohesion, tense and punctuation and to Jennifer Robson for assisting with the details of formatting the work.

The work of Professor Mary Marshall, Director of the Dementia Services Development Centre University of Stirling in promoting new concepts for the well-being of persons with dementia was inspirational throughout this study. The benefits of the ongoing research and materials provided by the Centre were greatly valued as a key resource. Helpful resources were also received from *Age Concern Scotland*.

I extend my gratitude to many friends and family who provided me with much needed and much appreciated support at various times.

Lastly and most importantly are the carers who participated in this study. It is a pity they must remain anonymous for their contribution cannot be measured by simply thanking them for their time. Their willingness to share their insights, experiences and struggles was a gift that I cannot hope to repay and without which this study would not have become a reality.

PROLOGUE:

Roots of the Concerns Informing this Research

The seeds of this research appear to have been planted during my years of experience as a newly qualified medical social worker, involved in the placement of elderly people in nursing homes, in Western Australia. This frequently involved me in four-way negotiations between the local general hospital, families, Department of Social Security and nursing homes. It was as a result of my experience with the elderly people during this time that I came to understand a great deal about the problems faced by dementia sufferers and their families when a nursing home placement had to be considered. Experience of dealing with one person in particular, namely Susan, had a decisive influence on my attitudes to people with dementia and concerns about their management in the community and in institutional care.

1 Susan's Story

When I first met Susan, she was 66 years old and had been living on her own for a few years following the death of her husband. She had no children and still showed some signs of being the formidable lady she was known to have been years before, when she was Matron of a sixty-bed regional hospital. Despite the fact that she was somewhat lost without her husband and without a job to occupy her time, Susan was not one to freely express how she felt about being on her own, or being dependent on others. Her attitude tended to be: "One must soldier on!"

The first indication that all was not well was when Susan would go out to do her grocery shopping at the local supermarket but fail to remember what she wanted to buy or why she was there. As this behaviour became more frequent, neighbours became more watchful and concerned, often describing her as 'going a bit off'. Susan's predicament was drawn to the attention of the district nurse who made a point of visiting her regularly. True to character, and despite episodes of forgetfulness and confusion, Susan did not take easily to suggestions that she should see her doctor. Having finally yielded to persuasion that she could benefit from a check-up or medication, she visited her doctor. The doctor explained to her that she was showing some early signs of senility. He prescribed medication to help her sleep and generally reduce her levels of anxiety.

She became much calmer for a period of time but she would often forget to take her medication. As time went on she showed more signs of anxiety and sadness. Yet, at other times, she would simply say: "I must pull myself together!" Despite neighbours keeping a watch on her, taking responsibility for chores around the house and bringing her food, they were greatly concerned about Susan living on her own.

Things came to a head about eight months later when Susan was found wandering outside her home partially clothed, at 2.30am. She was frightened, confused and unaware of where she was. She was admitted to the local general hospital and, following assessment, was transferred to Coburn Nursing Home two weeks later. Susan was admitted to Coburn on the basis of her inability to care for herself at home, and because of her senility, which was not considered advanced enough for admission to the psychiatric hospital. It was also chosen because there was a bed available and it was only five miles from Susan's home. In the absence of any immediate family members to take care of her, this also made it easier for neighbours and friends to keep contact with her.

Coburn was a nursing home that catered for twenty-five elderly men and women. Some patients were there because they could no longer live independently even though they were able to walk, interact with others and feed themselves but needed assistance with some tasks such as showering. Other patients were less mobile, interacted in a minimal way with others and required assistance with feeding, dressing, bathing and similar tasks. Then there was a small group of patients, like Susan, who were considered to be mild to moderately senile.

Catering for the varied needs and demands of this mix of patients was clearly a challenge, evident to any visitor to Coburn. Patients like Susan appeared to pose the biggest problem due to their tendency to wander, to engage in violent behaviour from time to time, to intrude on the privacy of other patients and to generally disrupt the environment of the nursing home.

Following admission to Coburn, Susan was stabilised on medication, causing her to behave in a subdued manner for the first couple of weeks. However, it didn't come as a surprise that she found it difficult to settle in to her new environment. Having been used to her independence and her own space, Susan found it difficult to share a room with three other ladies. She made no attempt to interact with them or other patients and did not welcome any interaction from them. She kept to herself most of the time while complaining about them to staff on a regular basis. Staff initially tried to attend to her complaints but found it difficult to reason with her. As the months went by, Susan seemed to become more

and more isolated. Staff found it difficult to engage her in conversation, usually approaching her with caution and avoiding her on occasions.

Throughout her first year at the nursing home Susan was frequently confused and agitated. While she was difficult to manage at such times, it was particularly when she saw herself in the role of 'Matron' that staff found her abusive behaviour difficult to accept and manage. She would criticise the nursing care, the food and the poor condition of the building. Over a period of months, Susan's outbursts became more frequent, often ending in violent behaviour toward the staff. As a result, tactics of restraint had to be employed to manage her, which was distressing for everybody concerned. Following one such episode and consistent complaints from staff, Susan was admitted to the psychiatric hospital for assessment. During the three weeks on the ward she was given heavy tranquillising medication and, following a period of stabilisation, was returned to Coburn.

Susan became very quiet, sitting for hours on end in a chair half-awake and half-asleep, with a tendency to become loud and abusive as the medication wore off. Staff assisted her with feeding, bathing, toileting and dressing. While they were still somewhat fearful of her, they attended to her needs, interacting only in a minimal way with her in terms of conversation. They found it difficult to connect with Susan. They felt at a loss to know what she was really thinking and feeling, or to what degree she was aware of her surroundings at any given time. As the weeks went by she became physically weaker but the staff ensured that she was kept comfortable. There were, however, lengthy periods of time when Susan was left unattended — due to the demands of other patients and the assumption by staff that she would make her presence felt if she needed anything.

She continued in this way for the following three years. As time went on she had fewer and fewer visitors. Those who did maintain contact found it difficult to engage her in conversation. They felt embarrassed at not being able to understand what she was trying to say, and were unsure that she recognised them anyway. Susan spent the last few months in bed, surviving on liquid-food and died rather suddenly early one morning after developing what appeared to be an infection.

At the time of her death Susan had few friends still alive. There was something particularly sad about the very small 'turn out' of people who came to say good bye to her at the local Anglican Church — mainly professional contacts like myself.

Eight months after Susan's death, all social workers in the region, including myself, were notified that Coburn Nursing Home was closing down for renovations and refurbishment and that we would be notified at a later date when it was ready for new admissions. However, the message on the grapevine was that the nursing home had been

condemned and patients had to be moved to other care settings in the area. I then recalled some of Susan's scathing and perhaps accurate remarks about the place, made in what may have been her more lucid moments. We never did receive any notification that Coburn was again open for business.

It is now almost twenty years since Susan died. While there may not be many people around who remember her well, her experiences as a senior nurse of living out the last decade of her life struggling to cope with the impact of a progressively debilitating disease, in a less than ideal environment and with staff ill-equipped to deal with people with dementia, is perhaps a story for our time!

2 Issues Emerging from Susan's Story

It is most likely that there is nothing exceptional about Susan's story that should set it apart from the experience of other people who were treated as senile at that time. In fact it is probably quite a typical scenario in the memories of some caregivers and family members. The story does, however, evoke feelings of sadness and dismay at the sense of Susan's struggle with living, bereft of any apparent joy or fulfilment. However typical the story may be, one of its most marked features is the way in which Susan became increasingly more isolated as the months and years went by. There appear to be several factors that combined to create the chasm that became a painful and marked feature of Susan's ongoing relationship with staff.

First of all, Susan was diagnosed and treated according to the medical model, which was the usual practice at the time. This meant, in effect, that there were no special guidelines for staff on how best to care for or relate to Susan, other than to administer prescribed medication and to apply standard nursing practice for managing the frail aged. Nursing staff were not trained in psychiatric nursing, and while some had years of experience with acute elderly patients, none had expertise in the field of dementia or 'senility' as it was known then. As a result, it was generally accepted that whatever the cause of the patient's confusion, be it senility or some other toxic-type confusion, the nursing management methods were the same in terms of how to approach the problems encountered.

When Susan was being admitted to Coburn she was accompanied by the district nurse and a neighbour — in the absence of any family. This in effect meant that throughout the admission process there was nobody present who could convey important details about Susan, such as:

- what her daily routine was like
- her preferences in food and clothing and
- how she liked to spend her time.

Understandably, the priority in everybody's mind was getting Susan admitted and ensuring her safety. Besides, it is most probable that everybody assumed Susan would have to fit into life at Coburn, with its routines, policies and practices, rather than Coburn fit her needs.

Soon after admission, staff encountered the same problems with Susan as they would with any confused person. She did not understand why she was in hospital and made numerous attempts to go home, which was an ongoing challenge for staff. Typical of confused patients, Susan often disturbed other patients and they her. This resulted in a great deal of anxiety for all concerned and frequently led to noise disturbance, loss of sleep and more aggressive behaviour — resulting in the need for chemical and/or physical restraint. While these experiences were upsetting for Susan and other patients, they were particularly painful and distressing for staff members. Invariably, following disturbing incidents, staff would discuss how such behaviour might be prevented in the future. Less tolerant staff often recommended that Susan was unsuitable for Coburn and should be shifted.

A doctor visited Coburn on a regular basis, but ongoing assessment of patients did not follow any pattern. Patients usually saw the doctor on a needs-basis. Besides, it was generally understood and accepted that little could be done for patients like Susan — other than keeping them comfortable and calm. When Susan became troublesome, she was given sedation. She was easier to manage when she was 'a little subdued' but was then more difficult to understand. As a result it was easier for staff to ignore or overlook her needs, or struggles to communicate, especially when they were pressed for time due to the needs of other patients.

All of this is perhaps best summed up in the frank admission of one carer when she said, “to be honest, patients like Susan are a damned nuisance.” There was no malice intended in this manner of speech, rather, it conveyed the truth about how staff felt. As they struggled on a daily basis to manage Susan, they understood so very little of what was happening to her, or how best to care for her obvious needs. Staff felt doing their best was not producing any apparent positive results with Susan, and that they tended to fail patients like her. These sentiments are probably quite true in terms of the degree to which the care delivered actually met Susan's needs as a person suffering from senility. Several factors appeared to have contributed to this situation in reality.

For example, Coburn Nursing Home was best suited to cater for the needs of frail elderly people who were reasonably mobile and in full possession of their faculties. It was therefore problematic for staff and other patients when somebody like Susan had to be accommodated. The issue was whether such patients should be integrated or segregated in terms of provision of care at Coburn. Opinions continue to be divided on the matter.

The medical model was helpful in diagnosing Susan's condition and ensuring that she had necessary and appropriate medication at all times. However, the model is based on the assumption that there is a medical explanation for this disease, a claim that has attracted strong opposition in recent years especially from the fields of psychology and sociology. This discussion will be elaborated on in Chapter 2 when attention will focus on current models of care for aged and dementing persons.

Staff were very dedicated to caring for Susan but were often quite distressed at the way interactions or events would frequently almost spiral out of control. This was because of their inability to reason with her or make sense of her ever increasingly incoherent speech. Staff members were not trained to understand the nature of Susan's disease nor its impact on her as she became increasingly debilitated by it. In addition they had to contend with the ongoing needs of other patients and all that that involved on a daily basis. They had to do the best they could with what they had available in terms of resources - personal and material. While some years have elapsed since that time and there have been many developments in approaches to care, staff groups still face similar issues and challenges today, and implications of these will be explored more fully in Chapters 7, 8, 9 and 10.

The past two decades have seen a surge of interest in ageing and dementia — from an academic and practice-focussed point of view. The impetus for this has come from a wide range of sources including concerned family members, social services, health and political bodies. This is so for a variety of reasons. These include the fact that dementia is now the fourth biggest killer disease after heart disease, strokes and cancer. World-wide there are also increasing numbers of people living into old age. As a result, there is a predicted increase in the number of people suffering from dementia. In addition, the work of social psychologists and sociologists has challenged the adequacy of the traditional medical approach to dementia, resulting in new understandings and approaches to care.

It is primarily these factors, coupled with the needs of dementia sufferers themselves, that continue to focus debate and decision-making on a series of critical issues such as: gaining access to adequate and appropriate resources; availability and support of suitably qualified carers (both paid and unpaid) and the need to cultivate care environments that are best suited to the needs of patients.

The need to provide suitable care for dementing elderly people has become both a complex and multi-faceted challenge. For example, gaining access to adequate and appropriate resources for aged persons living with dementia is likely to be perceived as a highly desirable aim, worthy of our total and unquestioning support. However, in reality the needs of these people in fact have to compete with the needs of sick children, terminal cancer patients and other special needs groups, in terms of priorities for government and health care spending. The practical implications of how lack of resources impacts on care staff as they try to manage hospital wards, to meet the needs of patients while ensuring best practice, are frequently drawn to our attention and sometimes sensationalised by the media. The impetus for this study was in part influenced by the desire to determine the reality with regard to nature of the challenges that carers had to manage on a day-to-day basis with respect to the practicalities of care delivery. In addition and for the reasons outlined above it was felt that the particular needs of elderly people which differed from other patient groups, not only warranted an approach that catered for their specific needs but, that there would be unique challenges of an ethical nature inherent in the process of care delivery given the competing financial demands and the often restrictive and inadequate health policies that applied.

The purpose of this study was *to provide an in-depth understanding of the contextual influences and ethical issues inherent in the delivery of quality care for people with dementia, based on an observational approach to care delivery and an exploration of any issues arising with carers.*

Before elaborating further on this aim it may be helpful to examine the political and health policy changes that form the backdrop to current approaches to dementia care in the United Kingdom. Based on the issues identified in Susan's story, a brief exploration will follow on the changing perceptions of dementia and the implications these have for caregivers, in terms of their training needs and competencies.

3 The Policy Context

Over the past two decades in particular, dementia has received increasing attention as a most significant issue for health care services. Much has been written about the nature of this disease, in terms of problems associated with the care of dementia sufferers and how dementia carers can be supported. Caring for people with dementia continues to present significant challenges to all health care professionals and to nurses in particular (Adams & Clarke 1999). From a demographic perspective the population of moderately to severely

demented individuals is projected to triple (Beck 1996). Of the 61,000 people in Scotland suffering from dementia, two thirds have mild dementia, one third have moderate to severe dementia, with 40-50% of these people living in institutional care at any one time (Age Concern Scotland 2002; Alzheimer Scotland 1996, p. 4). It is anticipated that by the year 2011 there will be approximately 72,806 people with dementia in Scotland, and 30,000 of them will require long-stay care places (Alzheimer Scotland 1996, p. 4). Clearly these statistics have implications for provision of care, how care costs will be met and resources allocated.

The same trends are becoming increasingly problematic for health care world-wide. In reports from the U.S. Bureau of the Census, the World Health Organisation and the United Nations the global trends in ageing, including demographic and epidemiologic transitions and increasing medical and social costs related to ageing reflect similarities with developments in the United Kingdom. For example, the health-care costs per capita for persons aged over 65 years in the United States and other developing countries is three to five times greater than the cost of persons aged under 65. In addition the rapid growth in the number of older persons, coupled with advancements in medical technology, is expected to create even greater pressure on the health and long-term care spending (Jacobzone & Oxley 2002). It is expected that the demands associated with long-term care will pose the greater challenge for both personal/family and public resources, with a projected increase of 20%-21% in the United Kingdom and the United States during 2000-2020 (Jacobzone 2000).

The reforms introduced by Government in the NHS and Community Care Act (1990), have had far reaching effects on the delivery of health and social services for elderly people in long-term care. The objective to shift the balance of care away from institutions and into the community has impacted quite directly on all elderly people suffering from dementia. This move has led to a re-definition of 'provision of care' as well as what it means to be a 'carer'. The shift toward the provision of care in the community seems to have been facilitated by a re-definition of dementia in terms of a move toward the recognition of the psychosocial aspects of the disease and an emphasis on a social model of care. These changes have been seen as a viable and opportune response to the changing NHS situation.

The implementation of the Community Care Act of 1990 appears to have had ramifications for all concerned with dementia care. According to Archibald (1997, p. 1) however, as a result of these changes, many dementia patients now remain in the community until late into the disease process, resulting in being finally admitted to care with complex needs. The net effect of this trend is that patients admitted to long-term care are increasingly

more disabled. This results in a flow-on effect of more serious problems having to be dealt with by staff.

There are ongoing concerns about the wide variations in the interpretation of the eligibility criteria for admission to NHS long-stay care, which may be swayed by factors other than the clinical needs of individuals (Alzheimer Scotland 1996, p. 33). The patchwork of funding sources is judged to be unfair and inappropriate, needing review and reform (Help the Aged 1996). The fact that the bulk of the health budget over recent years has been spent on dementia care – frail elderly care being an additional and significant cost – raises concerns for the management of future funding of care for dementing elderly people in particular. The projected growth in elderly people coupled with a decline in the number of working taxpayers, inadequate public resources and female adults available to provide informal care is both a concern and a challenge for fiscal managers of health care.

In addition, and coupled with the cost factor, is the issue of age discrimination, which has been reflected in very specific terms in various reports (Age Concern Scotland 1999). Discriminatory comments by doctors coupled with some indications of preference given to other groups in society and sentiments of ageism by nursing staff, have all raised concern about the lack of agreed principles for rationing, and the inequitable and ineffective allocation of resources in health care. Kath Melia also points out that the competition for resources does not end when the patient is admitted to hospital or place of care. According to Melia (1989, p. 40) nurses are exhorted to render the highest quality care to patients, while having to make decisions about the allocation of their time among patients. That involves rationing of care - decisions which are partly clinical and partly based on individual moral judgement: that is, 'adherence to conventionally accepted standards of conduct' (Collins English Dictionary 1998, p. 1010).

'The beliefs and values held about nursing and people will affect how care needs are identified, prioritised and managed' (Pickering & Thompson 1998, p. 196). Quality in nursing or health care is especially difficult to define because it is a human service which includes elements of subjectivity and intuition (Pearson 1998, p. 291). Quality care is then a normative concept rather than practice that can be simply defined according to clinical criteria. It involves making complex value judgements, based on ethical norms and the application of fundamental ethical principles. A key issue here is the degree to which the nursing profession must concern itself with problems requiring difficult ethical choices and the management of conflicting and adverse consequences that are at odds with the ethical responsibilities of nurses arising from policy changes.

What kinds of ethical criteria will be employed for resource allocation, and how will these actually impact on the practicalities of care delivered to a dementing elderly person in any care setting? What is the nature of the *practical* and/or *ethical* demands that nurses face on a day-to-day basis, in relation to competing demands for scarce resources? Given that nurses make clinical and ethical decisions on a daily basis that determine the quality of care offered to patients, with very little time or guidance to ensure the best outcome is achieved (Melia 1989, pp. 40-44), what might be the ethical consequences for the patient, for the carers and or for the hospital? The exploration of these and related questions are the central focus of this study.

4 Changing Perceptions of Dementia

For many years now dementia has been considered in terms of three categories: mild, moderate and severe. Each category, as the terms suggest, represents a progressively deteriorating state or experience of the disease. While these distinctions are convenient ways of conceptualising the development of the disease, there are more recently developed understandings of dementia and approaches to care, based on psychological, sociological and other care models. The current variety of models is reflective of dissatisfaction with the medical model, and developments in the social sciences and alternative approaches to health care.

Over the last decade professionals have recognised their indebtedness to Tom Kitwood for his leadership in the development of a radically different perspective on dementia, resulting in what has become known as 'a person-centred approach to care'. Underpinning this approach is the belief that the person must be considered in terms of their needs, unique life experience, network of relationships and their true self (Chapman & Kerr 1995, p. 19).

Despite the fact that there appears to be significant support for, and much to recommend, the Kitwood model, (as a holistic and all-encompassing approach to dementia care), it has been recognised by Kitwood himself and Norman (1999, p. 551), that this approach is still evolving and subject to new developments. Kitwood's thesis has received some criticism for its lack of scientific proof and tendency to depend significantly on anecdotal evidence supplied by carers. According to some of his critics his tendency to reject the bio-medical model as inappropriate while accepting the need for therapy is illogical (Harding & Palfrey 1997, p. 63).

In addition to the medical and psychological models, sociological approaches to mental health have also encompassed discussions on dementia care. These include structural, interactionist and ethnomethodological understandings of dementia. Because these different approaches to dementia, underpinned by different theoretical positions and knowledge, each have their merits and limitations, these will be explored in this study for the purpose of gaining a better understanding of the impact of dementia on patients and the implications of these different approaches for care delivery.

5 Caregivers - needs and competencies

Reference has already been made to the fact that there is usually a significant flow-on effect for carers when there are changes in care policies such as the admission of patients to long-term care. The staff who cared for Susan possibly understood very little about senility and found it increasingly difficult to converse with her in any meaningful way. However, they did know the importance of keeping her comfortable and pain-free as much as possible. Many carers of dementia patients today may have the exact same hopes or goals in terms of meeting their responsibilities to the people in their charge. However, other models of care demand additional expertise, skills and personal qualities in carers, irrespective of their training levels. For example, Kitwood spells out other requirements of a caregiver, which clearly demand greater resourcefulness in delivering care according to his person-centred approach model (1999, p. 118-132). In particular, this would include the ability to be present to people *'letting go of ...obsession with doing which often damages care work, and having a greater capacity simply for being.'* (Kitwood 1999, p. 119)

In Susan's story, there was evidence that staff appeared to struggle with how best to care for her, for a variety of reasons. For example, they had limited understanding of dementia as a disease and therefore found it difficult to relate to or communicate with Susan, other than in a very superficial way. They found it particularly challenging to manage Susan's behaviour in an environment that was not designed to meet the specific needs of patients with dementia. This placed added pressure on staff. Staff appeared to feel guilty about avoiding Susan as a way of coping with her negativity. This resulted in her becoming more isolated. While an abundance of research evidence now exists on dementia care, and a considerable investment of resources has been made to support both paid and unpaid carers, questions remain of how well these changes actually translate into a more effective delivery of care.

This study will explore many of the difficulties and problems to be overcome, or managed by staff, to ensure the successful implementation of the respective models or approaches to care. According to Holden and Wood (1995, p. 196), some approaches to care are very demanding on carers. These often require considerable imagination and courage to keep things going. They also point out that the vast majority of staff who work in dementia care are very enthusiastic and keen to give of their best, but they do need support - a point echoed in many other reports. Alzheimer Scotland (1996) list staff leadership and management support, staff training and good practice in care planning among the most important features, which affect the quality of dementia care for individuals. Each approach to dementia care requires certain kinds of special expertise, skill and knowledge.

Traditionally the delivery of health care has been primarily and almost exclusively focussed on the needs of the patients. Archibald (1997, p. 13) argues that if Kitwood's person-centred philosophy is to be the driving force of dementia care, then a holistic approach which extends to and *includes the needs of staff and carers* must be incorporated. She goes on to say:

"factors such as staff supervision and support, staff training (initial and ongoing), an exploration of staff skills and talents all need to be part of the philosophy and goals of Specialist Dementia Units" (Archibald 1997, p. 13)

Archibald's approach, which is radically different, places an equal emphasis on meeting staff and patient needs, based on a belief that caring for the needs of staff translates into better quality care for patients.

These themes too will be explored in this study. The approach adopted is based on awareness that employees vary greatly in their experience, skill and motives for being in this work. It also recognises that standards must be developed to evaluate different approaches so as to maintain the quality of care in order to safeguard the well-being of patients.

CHAPTER 1:

Demographic, Funding & Service Trends in Care Delivery

1.1 Introduction

In this chapter we will explore the demographic evidence on ageing and its impact on trends in service delivery and funding for health and social services. I will examine the data for Scotland, the United Kingdom and Europe (in some cases). The range of topics covered in this survey include:

- population projections and prevalence rates of dementia in the UK and in particular in Scotland
- numbers of people with dementia according to age and gender
- statistics on projected estimates of growth in the number of people with dementia
- data on the living circumstances of people with dementia including levels of dependency and the types of ongoing assistance required by people
- an overview of care settings including information on patient mix and numbers
- an examination of the impact of building design, and the physical environment, on the form and quality of care delivery
- an exploration of long-term care funding and details on community care expenditure for older people
- a discussion of the issues involved in the assessment of the quality of care, and problems in the application of current standards
- staff registration and inspection practices as means to promote better standards of care for elderly people, and
- an examination of some new initiatives.

1.2 Increasing Longevity - a burden or a blessing?

National and international data, including reports from the World Health Organisation and the *Human Development Report* of the World Bank emphasise that there is a world trend

towards, and increase in, the numbers and proportion of elderly people in all member states of the United Nations.

Though increasing longevity is not necessarily widely regarded as one of the great achievements of the twentieth century, it is certainly a notable fact. Major advances in the fields of both clinical and public health medicine and improvements in the quality of health services have certainly contributed to increased life-expectancy in most countries. *The Human Development Report* demonstrates that improvement of health status is linked to improvements in the economic and social conditions of people in many countries and, in particular, to improved education of women. Gerontological studies have also led to better understanding of the ageing process by promoting demographic, epidemiological and clinical research on ageing and dementia. All these, it has been argued, have contributed to improvements in the health of older people over the last two decades.

Many hypotheses have been advanced on the possible causes of the trend of accelerated improvements in later life survival. Major advances in the field of clinical medicine, including the introduction of new treatments for the most common diseases and causes of death, are frequently cited as the key factor contributing to people now living longer. However, Warnes (1996, p. 30) argues, in his discussion of 'the demography of old age', that the changes are primarily a consequence of improvements in public health, encompassing better nutrition, hygiene, preventative medicine and housing conditions. Warnes points out for example that due to the halving of the infant mortality rate throughout Great Britain from 1900-1950, it is highly probable that people born in the early 1930's (and now entering their 70's), benefited from these changes, - experiencing fewer childhood privations and better nutrition than their parents.

Living longer is not always an unqualified blessing. Living into old age brings with it certain challenges such as, how to manage physical frailty, the multiple disabilities and complex disorders of old age. Nevertheless many people who have survived numerous difficulties and challenges during their lives are often quite resilient in old age. Some of these people have had to adapt to change and to learn new ways of doing things to solve life's problems. Despite the fact that elderly people have the greatest accumulation of life experiences, quantitatively and qualitatively, we live in a society that does not respect this acquired wisdom. Instead we recognise and reward youth, physical beauty, wealth and productivity. This implicit and sometimes explicit ageism in Western society means that ageing is associated with being socially and economically redundant, a perspective that appears to be primarily responsible for legitimising the marginalisation of the elderly (Heath & Schofield 1998, p. 13).

1.3 Population Projections and Prevalence Rates of Dementia in the UK

There are important implications for health and social services planning that at least 20% of the population in most prosperous industrialised countries will be over 65 by the year 2030 (Glennerster 1996, p. 1). It is predicted that about a half of all women and a third of all men who turn 65, will need intensive intervention and support for two or more years before they die. These projections are becoming a more key element in the financial calculations of families, health care providers and governments. The growing demand for health and social care services for ageing populations has been identified as a critical issue for the European Union (EU) in the 21st century. While increases in the population of elderly people may occur at different rates in different countries, it is predicted that 20.7% of people will be over 65 and 5.7% over 80 years in the EU by 2020 (Alzheimer Scotland 1999). The growth in the older population groups in the UK has followed the same trend as elsewhere in the developed world and has been a matter of debate for some time. While increasing longevity may be an achievement of modern society, on its own it is not enough. It is dependent upon adequate funding, maintaining health and fitness and the availability of good social, medical and nursing care — all of which require planning.

The focus in this chapter will be on the levels of dependency of the older age groups and their need for health and welfare services in the UK, and in Scotland in particular. As people grow older their need for care increases, sometimes quite dramatically. Aside from needs directly associated with the ageing process, some older people also need more assistance and care for conditions which they have acquired such as chronic health problems, physical or learning disabilities and tendencies toward depression. Hence the growth in the ageing population has considerable implications for future human services of all kinds.

In 1998, the population of Scotland was estimated at 5,120,000, of whom almost 20% were over the age of 60, while approximately 18.75% were over pensionable age (which is 60 for women and 65 for men) (General Register Office for Scotland 1998). Taking into account the change in retirement age for women (which will be 65 beginning in 2010), it is predicted that by 2016, 21% of the total population, ie. 1,074,000 people will be over pensionable age, and that percentage is estimated to rise to 24% by 2036 (Government Actuary with Registrars General 1996).

In the UK, 70% of the people who had to stay in hospital after a fall were over 65, while 15,000 people aged 65+ die in an accident at home every year (Department of Trade and Industry 1998). Of the total population of Scotland, it is estimated that 70,810 people

aged 65+ are visually impaired (Royal National Institute for the Blind as cited by Age Concern Scotland 2000, p. 10). In addition there are an estimated 528,000 people aged 60 or over who have some degree of hearing loss while 46,000 of these are severely or profoundly deaf (Royal National Institute for Deaf People as cited by Age Concern Scotland 2000, p. 10).

These population projections and disability estimates reflect something of the needs of older people for long-term care, and since health and welfare needs account for the highest proportion of budget expenditure these have direct implications for the future funding of such care. These projections must be also of particular interest and concern for dementia care policy makers and dementia care providers, particularly as there is now a series of prevalence studies indicating that prevalence of dementia increases steeply with age (Royal National Institute for Deaf People as cited by Age Concern Scotland 2000, p. 10). While the estimates of elderly people living with dementia are quite significant, and the numbers do increase with age, many studies advise us to guard against equating old age with dementia. In other words dementia is not necessarily a normal part of ageing and, according to Jacques and Jackson (2002, p. 2), dementia is a minority condition even among people in their 90's.

Table 1.1: Prevalence of Dementia in the Community (adapted from EURODEM data 1995)

| Age Group (years) | Percentage with dementia | Percentage without dementia |
|-------------------|--------------------------|-----------------------------|
| 30-59 | 0.1 | 99.9 |
| 60-64 | 1.0 | 99.0 |
| 65-69 | 1.4 | 98.6 |
| 70-74 | 4.1 | 95.9 |
| 75-79 | 5.7 | 94.3 |
| 80-84 | 13.0 | 87.0 |
| 85-89 | 21.6 | 78.4 |
| 90+ | 32.6 | 67.4 |

Source: Jacques and Jackson 2000, p. 3

The statistics in Table 1.1 above show the numbers of people with dementia at any one time. The figures primarily reflect the numbers of people who are living with moderate to severe dementia. Understandably these groups would be easier to estimate since they are more likely to be known to services and to be receiving some form of care. These statistics however, according to Jacques and Jackson, may considerably underestimate the numbers of people living with mild dementia, since they may be shielded by informal carers and may be more difficult to diagnose. The figures in Table 1.1 are a summary of a large number of

community surveys of elderly people, indicating that by far the majority of these people are mentally healthy.

There are an estimated 61,700 people with dementia in Scotland at present, 92% of whom are aged 65+, 72% are aged 75 or over, and it is expected that by the year 2011, 67,500 people will have dementia and 61,600 will be over the age of 65 (Alzheimer Scotland 1999). The significance of these statistics and other demographic trends will be explored below for the purpose of understanding the scale of need for services for people suffering from dementia. The nature of different dependency levels and practicalities of dealing with patients will be discussed in relation to the variety of settings in which continuing care for people with dementia is provided. The issue of costs will be explored in relation to accommodation and day-to-day expenses of providing care. Attention will also be drawn to indirect costs such as foregone earnings by patients, partners or carers as well as the emotional demands of providing care.

Finally, recognising the increasing competition for scarce resources and the obligation to ensure that standards are maintained in all areas of service delivery, consideration will focus on the legislation and other regulations that will need to be in place to safeguard patient care and the protection of their rights. This Chapter is intended to provide a brief summary, rather than a comprehensive analysis of issues, by considering important evidence from demographers, actuaries and economists on the funding and provision of quality care to older age groups.

1.4 Prevalence of Dementia in Scotland

Information about the prevalence of dementia has only been available for the last two decades, with improvements in the availability of reliable statistics since the early 90's due to more rigorous research. However, the picture can still be a little confusing as shown in Table 1.2 below.

This table shows age-specific prevalence of dementia in percentages based on three different studies: the European Community Concerted Action on the Epidemiology and Prevention of Dementia (EURODEM) study by Hofman et al (1991); the Framingham (USA) study (Kokmen et al 1989) and a literature analysis by Jorm et al (1987).

Table 1.2: Age Specific Prevalence of Dementia (%) in the Elderly

| | 66-69 | 70-74 | 75-79 | 80-84 | 85-89 | 90-94 | 95-99 |
|-------------------|-------|-------|-------|-------|-------|-------|-------|
| EURODEM | 1.4 | 4.1 | 5.7 | 13.0 | 21.6 | 32.2 | 34.7 |
| Framingham | 0.9 | 2.0 | 4.3 | 8.0 | 16.3 | 16.3 | 16.3 |
| Jorm et al | 1.4 | 2.8 | 5.6 | 10.5 | 20.8 | 38.6 | |

Source: Harvey 1998

While some variations exist in the results of the prevalence studies in Table 1.2 above, there does appear to be broad agreement that dementia increases with people over 65, and that the rise is particularly marked in groups 80 years and over. However, the picture can be confusing, this being primarily due to the use of different definitions of dementia and variations in assessment strategies, which will be discussed in Chapter 2.

The EURODEM statistics are of particular relevance to this study and the group are considered to have provided robust prevalence rates (Hofman et al 1991). There are a number of reasons why these estimates are considered reliable and therefore valuable. Firstly, EURODEM applied rigorous criteria to the re-analysis of the original information from twelve prevalence studies carried out throughout the 1980's in Europe and to the definition of dementia, based on individual examinations of people. In addition, the EURODEM statistics are based on studies which included people in long-term care — living in institutions such as residential or nursing homes or long-stay hospitals. Finally, these statistics are considered useful because they provide details of prevalence rates as they relate to age groups and gender.

However, there are perhaps some doubts which may be raised regarding the claim as to the robust nature of the EURODEM prevalence rates. For example, while the study was large, it was based upon sample surveys, so any estimates are likely to have a margin of uncertainty around them (Hofman et al 1991, p. i). The difficulty of procuring accurate figures is also noted, because many people with dementia remain undiagnosed until such time as the illness reaches a stage where behaviours become a problem and the dementia is fairly advanced (Alzheimer Scotland 1996, p. 13). Finally, the extent to which there are people with dementia in every facility for older people is difficult to assess given that, for example, in many acute hospital wards, only the presenting medical or surgical problem is recorded for statistical returns (Elgar & Marshall 1998). The living circumstances of people with dementia, the range of services available and the costs involved in the provision of care are important aspects of the overall profile of the prevalence of dementia in Scotland.

Table 1.3 below presents the EURODEM 1996 prevalence rates for dementia by age group and gender for Scotland. Details are outlined for each sex for the age group 30-59 and

then by five-year age bands from 60-64 to 95-99, reflecting the fact that the prevalence of dementia rises sharply with age.

Table 1.3: Number of people with dementia in Scotland according to age groups and gender

| | 30-59 | 60-64 | 65-69 | 70-74 | 75-79 | 80-84 | 85-89 | 90+ | Total |
|----------------|-------|-------|-------|-------|-------|--------|--------|-------|--------|
| Male | 1,616 | 1,921 | 2,367 | 4,140 | 2,922 | 4,233 | 2,850 | 1,532 | 21,580 |
| Female | 955 | 638 | 1,437 | 4,590 | 6,207 | 9,486 | 9,487 | 6,774 | 39,576 |
| Persons | 2,571 | 2,559 | 3,804 | 8,730 | 9,129 | 13,718 | 12,339 | 8,306 | 61,155 |

Source: Alzheimer Scotland adapted from EURODEM 1996¹

Minor discrepancies in the totals in Table 1.2 are due to independent rounding of figures. As observed earlier and in alignment with other prevalence studies, Table 1.3 shows that the prevalence of dementia increases with age highlighting a marked rise in the statistics for those groups over 80 years of age. Again in line with other studies, Table 1.3 reveals gender differences both in the prevalence rates of dementia and in the overall number of people with dementia. Below the age of 70 years the prevalence of dementia in men is almost twice that for women. In the 70-75 age-bracket the rates for men and women are almost the same, while women outnumber men significantly from the age of 75 onwards. This last statistic is attributed to the fact that fewer men live beyond the age of 75. Although the prevalence rate for people with dementia in the 70-75 age-group is about the same for men and women, there is a gender difference for specific types of dementia. According to Jorm et al (1987) women are likely to be represented in the Alzheimer's Disease category, while men are more likely to have vascular dementia.

Table 1.4 below outlines the projected increase in the number of people with dementia for the next 10 years.

¹ Table 3 shows the exact figures calculated using EURODEM prevalence rates and the Register General Scotland's populations estimates. Although EURODEM is a large study it is based on a sample of surveys, and as a result its estimates are likely to have a margin of uncertainty according to Alzheimer Scotland. The latter advises it is sensible to think of their being 'around 61,000' people with dementia.

Table 1.4: Projected estimate of growth in the number of people with dementia in Scotland by age group

| Age Group | 1995 | 2000 | 2005 | 2010 |
|--------------|--------|--------|--------|--------|
| 30-59 | 2545 | 2657 | 2675 | 2563 |
| 60-64 | 2570 | 2596 | 2676 | 3206 |
| 65-69 | 3815 | 3758 | 3827 | 3960 |
| 70-74 | 8805 | 8678 | 8648 | 8879 |
| 75-79 | 8781 | 9936 | 9948 | 10,030 |
| 80-84 | 13,862 | 13,080 | 15,058 | 15,469 |
| 85-89 | 12,079 | 13,099 | 12,747 | 14,875 |
| 90+ | 7840 | 10,191 | 12,097 | 12,891 |
| Total | 60,298 | 63,994 | 67,675 | 71,873 |

Based on population projection by D S Gordon, 1996 (General Register Office for Scotland 1998)

Table 1.4 shows that dementia increases with age and that the prevalence of dementia increases markedly in the 80-84 age group. These statistics are comparable with another study by Alzheimer Scotland estimating the number of people with dementia in Scotland 1981-2011. The study, which was based on trends over the 15 years period from 1981-1996, indicates that the trend up to 2011 will remain about the same. The findings of the study also revealed that the gender differences in the number of people with dementia are predicted to continue along similar lines up to and possibly beyond the year 2011. However, according to DS Gordon, the similarity in the expected figures for the next decade should not be interpreted to mean that things will remain the same. Rather, he is of the opinion that much will have to be done simply to maintain present levels of services (Gordon 1999, p. ii). While Table 1.4 presents estimates of the number of people with dementia under the age of 65, there are relatively few studies or statistics available on people in this age group.

The Alzheimer's Disease Society estimated in 1992 that approximately one person in every thousand in Britain experiences early onset of dementia. There is now a greater tendency to look at dementia in relation to the age of the patient, recognising the needs of younger people to be different from those of people in older age groups. It is also generally recognised that younger people with dementia often have a dual disability such as learning difficulties or Down's Syndrome. The needs of younger people with dementia can challenge service providers to find appropriate care solutions.

We will now explore the nature of dependency levels of patients with dementia, and their living circumstances, with reference to all age groups concerned.

1.5 Living Circumstances of People with Dementia - Levels of Dependency

The findings from two studies conducted in central Scotland estimated that the percentage of the total population with dementia in all forms of long-stay care is between 40 and 45% (Gordon, Carter & Scott 1997). This figure includes those with a secondary diagnosis of dementia in NHS geriatric long-stay care (Alzheimer Scotland 1996). The steep increase in prevalence of dementia by age, linked with increases in the oldest age groups, tends to suggest that increasing numbers of people with dementia are most likely to require some form of institutional care in the final stages of the disease.

Criticisms of care systems and concerns about social security spending were at the core of the NHS and Community Care Act Reforms of 1990. The new funding system introduced in 1993 saw a shift of responsibility for care management to local authorities — based on a system of individual need assessment. The aim was to provide users with a choice but, in practice, there were problems with the system of paying for care. This was due to increased pressure on social care services and a significant reduction in long-stay NHS beds. This in effect meant that older people, and dementia sufferers in particular, found themselves trapped at the interface between health and social care. These problems were reviewed by the Royal Commission on Long-Term Care in 1999, which recognised the need for a coordination of services and support from a variety of community agencies. The Commission was made aware that the way forward depended on effective and ongoing assessment of individuals, support for carers and inter-agency collaboration, while ensuring that the needs of the person with dementia are central to all the support provided (Cameron & Chapman 2000).

Over the past decade numerous studies have attempted to present reliable estimates of people with dementia by place of residence. This continues to prove problematic for some of the reasons mentioned above in relation to different health and social care approaches to service delivery, and to the absence of an agreed definition of dementia and standard assessment strategies. The work of Schneider et al (1993) in England, and Gordon et al (1995) and Gordon and Spicker (1997) in Scotland, are still considered the most reliable sources from which estimates and projections can be made. As outlined in Table 1.5 below estimates from the three studies mentioned indicate that 55-63% of people with dementia lived in the community, the majority of whom were living with others.

Table 1.5: Percentage of people with dementia by place of residence

| Place of residence | Schneider et al 1993 | Gordon et al 1995 | Gordon & Spicker 1997 |
|-------------------------|----------------------|-------------------|-----------------------|
| In the community | 63 | 55 | 55 |
| Alone | 13 | 21 | 25 |
| With others | 50 | 34 | 30 |
| In institutions | 36 | 45 | 45 |
| Residential Care Homes | 19 | 15 | 12 |
| Nursing Homes | 7 | 8 | 13 |
| Hospital settings | 11 | 22 | 20 |

Source: Scottish Forum for Public Health Medicine 1997

The discrepancy between estimates in these studies may be due to a variety of factors. For example, the Schneider study was based in England in 1985-1986, while data from the other studies was gathered in Scotland almost a decade later. It is also possible that the studies were based on different understandings of dementia and different assessment strategies. Differences in policies for admission to institutional care, between England and Scotland, may also account for some variations in these estimates.

Anomalies also exist between the Gordon et al study and official statistics as outlined in Table 1.6 below.

Table 1.6: Anomalies in the balance of care data

| | Living in long-stay care | Living in the community |
|----------------------------|--------------------------|-------------------------|
| Official statistics | 33% | 66% |
| Gordon et al | 40-45% | 55% |

Source: Alzheimer Scotland 1996

Gordon estimated that approximately 40-45% of people with dementia lived in institutions. He disagrees with Jacques and Jackson who appear to hold the view that only a small minority of people with dementia live in institutions. According to the latter, surveys show that the ratio of dementia sufferers at home to those in institutions is at the very least 4:1 and is more likely to be as high as 7:1 (Jacques & Jackson 2000, p. 90) Jacques and Jackson go on to suggest that the figure is likely to continue rising given that the number of sufferers is probably outstripping the modest number of institutional beds available. In support of his estimate of 40%, Gordon points out the level of institutional provision of care may vary locally, but for larger areas the balance of care for elderly people is between different types of institutions. For example in England there has been a faster reduction of continuing care than in Scotland where there has been a greater increase in residential and

nursing home care (Hunter 1997, pp. 46-47). It does seem however that the overall availability of institutional care is about the same for England and Scotland.

According to Alzheimer Scotland (1996), the number of persons living with dementia in residential homes is generally underestimated by professionals. This is believed to be the main source of the difference in the official statistics and relates to differences in approach to gathering the data, which tend to be based on functional disabilities of residents in nursing homes and residential homes, and not on diagnostic labels. However, it is believed that Scottish Health Statistics data on the number of inpatients with dementia in mental illness hospitals are accurate and reliable. Recognising the fact that margins of error may exist in study findings, it is the breakdown of the overall statistics into dependency levels of individual patients that provides a better sense of the demand for services.

In a survey of the Forth Valley, Scotland, Gordon et al (1995) asked various services and agencies to identify the number of people over 65 who had memory problems or confusion - otherwise known as people with dementia. A total of 2060 people were identified. A needs assessment, based on a checklist identified by Levin et al (1989), was conducted primarily by postal questionnaire with a sample of 195 formal carers and 91 informal carers (Downs & Marshall 1997). Based on the Gordon et al Forth Valley survey and adapted by Downs and Marshall, Tables 1.6 above and 1.7 below reflect the percentages of people with dementia by place of residence. In addition the table shows the kind of assistance required and the frequency of need for particular services.

Table 1.7: Percentage of people with dementia by place of residence and levels of dependency

| | Community Household (n=91) | Residential Care Home (n=43) | Nursing Home (n=54) | Psychiatric Ward (n=49) | Geriatric Ward (n=49) | Weighted Total Percentage |
|---|-------------------------------|---------------------------------|------------------------|----------------------------|--------------------------|------------------------------|
| Mobility | 29 | 56 | 81 | 84 | 86 | 57 |
| Personal Care | 73 | 98 | 100 | 100 | 100 | 89 |
| Personal Care at Night-time | 30 | 66 | 94 | 98 | 92 | 62 |
| Domestic Assistance | 80 | 92 | 97 | Not asked | Not asked | ----- |
| Behaviour Problems | 61 | 95 | 80 | 94 | 78 | 76 |
| Behaviour Problems at Night-time | 33 | 77 | 74 | 82 | 69 | 57 |

Source: Adapted by Downs and Marshall from Gordon et al 1995

Note: Under the heading 'Community Household' in Table 1.7 above, n=91 refers to the number of informal carers involved in the study, while the numbers in brackets under all other headings represent the number of formal carers who responded from each institution.

This table shows that 29% of people in the category Community Household were identified by informal carers, as having problems with mobility. Mobility was a difficulty for more than half of people with dementia, while 89% of them needed some form of assistance with personal care. Two thirds of the total number required personal care assistance to live in institutional care settings. Night time help was required by 62% of people and 76% needed attention due to behaviour problems. Approximately 50% of the total number with behaviour problems were cared for in hospitals or nursing homes. Night time care and attention was required by 57% of people with dementia due to behaviour problems.

From these statistics it can be deduced that the people in the study were significantly dependent on others for assistance and were probably suffering from moderate or severe dementia. Because there is no mention of counselling or other support programs in the study, it is not clear what some of the categories might actually mean: for example, 'behaviour problems', which will be discussed in relation to Table 1.8 below.

Table 1.8: Percentage of people with dementia by place of residence and the types of assistance required more than once daily

| | Community Household (n=91) | Residential Care Home (n=43) | Nursing Home (n=54) | Psychiatric Ward (n=49) | Geriatric Ward (n=49) | Weighted Total Percentage |
|---------------------|-------------------------------|---------------------------------|------------------------|----------------------------|--------------------------|---------------------------|
| Mobility | 25 | 34 | 74 | 71 | 86 | 49 |
| Personal Care | 56 | 60 | 91 | 98 | 90 | 72 |
| Domestic Assistance | 77 | 90 | 97 | Not asked | Not asked | ----- |
| Behaviour Problems | 45 | 91 | 57 | 69 | 57 | 59 |

Source: Adapted by Downs and Marshall from Gordon et al 1995

Table 1.8 indicates that 49% of people need assistance more than once a day with mobility, most of whom live in either nursing homes, psychiatric or geriatric wards. As might be expected, high proportions of people who live in those settings also require assistance with personal care at least once a day. There is also a significantly high number of people in the community, of whom 56% require personal care assistance on a daily basis. A considerably greater number of people in the community (77%) need regular assistance with domestic tasks. Obviously this area of assistance does not apply to people in psychiatric or geriatric wards. To draw any meaningful conclusions on the statistics for problem behaviour,

it would be helpful to know what was classified as 'behaviour problems', and by whom. In other words, the tolerance levels of carers, in their approach to managing behaviour problems, may have influenced the findings in Table 1.8. For example, if a patient has a tendency to be aggressive but is kept sedated most of the time and is therefore easier to manage, is that person classified as having behaviour problems? On the other hand if a patient calls out to the nurse on a constant basis in a high-pitched irritating voice - behaviour which may annoy one nurse but not another who chooses to ignore it - is it to be classified as a behaviour problem?

It must be recognised that the categories identified in Tables 1.7 and 1.8 are broad and as a result it is difficult to draw any specific conclusions regarding the number of people requiring palliative type care, for example. However, the tables do give some indication of the levels of dependency of people with dementia and their places of residence. The issue of demand for and the supply of financing of long-term care for elderly people has been the focus of a number of studies in recent years and continues to be subject to analysis and review.

We now turn to consideration of some of the costs involved in funding care settings for elderly people.

1.6 Care Environments

The provision of long-stay specialist care has been a feature of dementia care since the 1980's. This development has been largely driven by demographic changes, which have resulted in ever increasing numbers of people over the age of 65 years needing care, coupled with changes in health and government policies which will be explored further later in this chapter. The implementation of the Community Care Act (1990) and the closure of large psychiatric hospitals have resulted in the relocation of some people with dementia being relocated to community settings.

Since the early 1990's, and following the trend in the U.S. during the 1980's, the UK experienced a proliferation of specialist dementia units (SDU's). The range of units is wide, including residential and nursing home SDU provision. Some units are purpose-built stand-alone buildings specifically designed to meet the needs of people with dementia and their carers. Others are simply defined spaces such as wards within hospitals or nursing homes, which allow for the distancing or clustering of residents with dementia. A good example of

the wide variation in care environments is shown in the environmental review in a 1997 pilot study examining the use of anti psychiatric drugs in the Falkirk and Stirling areas.

The eight care settings, which were randomly selected from a cross-section of various hospitals and nursing homes within the Falkirk and Stirling areas comprised: two long stay hospital wards and two nursing homes for older people as well as two long stay wards and two nursing homes for people with dementia. Each category contained one care setting from Falkirk and one from Stirling. All care settings cared for people with dementia.

Table 1.9: Environmental Review (MacDonald & Teven 1997)

| Location | Building/ Ownership | Beds | Internal Environment | Patients |
|----------|--|------|--|---|
| Area A | A new, purpose built nursing home, owned and run by two experienced nurses | 32 | Quiet and homely | Dementia (including challenging behaviours mixed sex) |
| Area B | A large, newly built nursing home, owned by a private company | 60 | Large and spacious. Split into levels, quiet but felt 'empty' | Dementia (including challenging behaviours mixed sex) |
| Area C | A hospital ward in the grounds of an old psychiatric hospital NHS Trust | 25 | Homely, but noisy and disruptive | Dementia (including challenging behaviours) Males only |
| Area D | A small newly built hospital ward. NHS Trust Psychiatric Hospital | 20 | Quiet and homely | Dementia (including challenging behaviours) Females only |
| Area E | A large nursing home based in an old mansion owned by a private company | 58 | Large and spacious, numerous rooms and corridors. Lacked homeliness. | Wide variety, some dementia, mixed sex. |
| Area F | A small newly built nursing home owned by a private company | 23 | Quiet, comfortable and homely. Confined | Older people, some dementia mixed sex |
| Area G | A small established hospital ward NHS Trust General Hospital | 20 | Very clinical (old orthopaedic ward) | Older people, some dementia mixed sex |
| Area H | A small hospital ward, in an old psychiatric general hospital NHS Trust | 17 | Restrictive and confined | Older people, some dementia mixed sex |

In this study the findings indicated that the environments varied widely, but were mostly comfortable, pleasantly decorated and with no evidence of major restraints. All areas had some people with dementia and all areas were mixed with the exception of Areas C and D. The researchers also noted that staffing levels were very similar with an average ratio of one member of staff to every six residents.

Despite the enthusiasm and popularity of SDU's, few researchers have rigorously examined their impact on quality of care (Archibald 1997). In a 1991 study of Special Care Units, which examined factors contributing to quality of care for people with dementia, Gold et al went some way towards helping people to identify quality issues, based on the assumption that SDU's should be different to traditional nursing home care. The study looked at factors such as:

- staff-resident interaction
- staff attitudes to residents
- staff stress
- administrative philosophy and attitudes to residents
- attitudes to staff training
- odours and cleanliness.

The outcome of the study was the identification of a typology of care settings consisting of eight distinct types, each representing a unique model of staff, residents and other features.

At one end of the range an ideal type emerged, which has an administration knowledgeable about dementia, a therapeutic rather than custodial approach to care, staff highly experienced in this kind of care and an equal concern for staff and residents. The environment is homely, does not smell and patients are assisted and encouraged to personalise their surroundings (Archibald 1997, p. 5). At the other end of the range a contrasting and less appealing picture emerges. The features of this type include left-over furniture; dirty, unkept units with urine and faecal odours evident and residents poorly groomed and dirty. In this type staffing levels are low, residents are often alone with few friends or family as advocates and there is a high use of chemical and physical restraint. Finally this type of unit usually admits people with mild, moderate and severe dementia which, when combined with features already identified frequently results in challenging behaviour in residents with serious physical problems (Archibald 1997, p. 5).

Considerable emphasis, over the past few years, has been placed on the importance of environmental design in the lives of people with dementia, and from this standpoint, the majority of care settings probably fit somewhere between the two extremes in the range identified in the Table 1.1 profile above.

Based on design principles, outlined by the Dementia Services Development Centre, Stirling, buildings should make sense to patients and be easily understood. Such environments should be therapeutic and, of course, safe. Finally the design should include quality environments for staff and those caring for people with dementia (Marshall 1997). It

is not possible to cover all aspects of design here but it is important to draw attention to the fact that building design can assist or hinder people with dementia. There is evidence to support the view that the more attentive and sensitive designers and carers are to the needs of people with dementia, to ensure that care environments are relaxed and secure, the more likely it will be that patients will be able to communicate effectively (Goldsmith, Kindred, Innes & Chapman 1997, p. 28).

1.7 Funding Long Term Care

As a result of Government and NHS policy changes in the early 90'S, the official aim has been to shift the balance of care away from institutions and into the community. This shift has been particularly significant for elderly people, including those with dementia. The community care policy continues to stress the importance of maintaining people in their own home in environments that are as homely as possible. However, as reported by the Accounts Commission (2000) a large proportion of the £540million spent by local authorities on community services for older people in 1998/99 went to residential and nursing home care. As stated in the report, this indicates a strong bias that still exists towards institutional homes of care for elderly people.

Table 1.10: The balance of Community Care Expenditure for Older People

| | |
|-------------------|-----|
| Residential Care | 36% |
| Nursing Home Care | 23% |
| Day Care | 4% |
| Home Care | 29% |
| Other | 8% |

Source: CIPPA, Personal Social Services Statistics — 1998-99 Estimates

As shown in Table 1.10, 36% of the overall budget was spent on residential care and an additional 23% on nursing home care, which accounts for almost 60% of expenditure on elderly people. Because expenditure on institutional care is almost twice that on Home Care (29%), the growing cost of home care is becoming a matter of a concern, as will be indicated later.

A study by Bosenquet, May and Johnson (1998, p. 12) estimated the then current annual costs of caring for Alzheimer patients in the UK to be between £5,400million and £5,800million. There are however some items such as private housing and personal

expenditure included in this figure which are not directly related to provision for Alzheimer's Disease. Of this total budget for people with dementia, the NHS and local authority pay about 42%, while the remainder is paid by the Department of Social Security or by patients and their families (Briggs & Askham 1999, p. 70). The cost of providing this care up to the year 2021 is expected to increase to between £7,200 and £7,700 million (Briggs & Askham 1999, p. 70). As the study by Bosenquet et al suggests much of the future burden of care will probably rest with informal and professional carers in residential settings, since it is expected that the advent of more effective drug therapy may reduce the need for many patients to spend extended periods of time in institutional care.

The issues of growing demand and the financing of long-term care for elderly people have been the focus of a number of studies in recent years. While the studies do not appear to have produced any definitive answers, they do serve the purpose of encouraging more debate on critical elements that should underpin future financial planning. A central factor in this debate is the predicted demographic change, namely, the expected rise in the number of elderly people and those likely to experience dementia. The urgent question is how to ensure adequate funding of long-term care for the next decade(s). A second factor which is key to this debate, mentioned earlier, is the issue of the balance of care. Correct diagnosis of people and appropriate placement to ensure the best possible care are fundamental to ensure that the statistics needed for financial planning are accurate and reliable. Uncertainty about the future levels of informal care that can be provided by family, friends and neighbours poses a problem when making these calculations.

The Joseph Rowntree Inquiry into meeting the costs of continuing care revealed a number of important trends: the decline in the number of available care providers, as women (traditionally the main care providers) choose to be in work, and changes in family structure resulting in increased numbers of single-parent and divorced women having to care for their own children (Rowntree 1997, p. 3). These developments are likely to increase the demand for paid professional care for the increasing number of elderly people in the population.

Another key issue in the financing of long-term care is the management of the interface between health and social care and their different funding, and changing regimes associated with balancing the finance between public funding and private resources. Based on recommendations from the Royal Commission on Long Term Care of the Elderly, the Scottish Executive is about to state its position on a number of funding concerns and in particular on the issue of the appropriate balance between private funding and public funding.

Last but not least the issue of older people's expectations in terms of care standards and the range of services required is another factor which influences the funding of long-term care (Audit Commission 1997). So far official discussion has centred on the funding of care for elderly people in general, which is taken to include people with dementia. Over the past decade, however, an increasing number of studies such as Holmes et al (1998), Livingstone et al (1997), Schneider et al (1993) and Keen (1993), have focused on the issue of determining the cost to the economy of caring for people with dementia.

As might be expected, it is difficult to determine or predict costs for future planning. Schneider et al concur with a study by Dellasega and Nolan (1997) that it is generally perceived that people with dementia should be cared for in the community and be encouraged to retain their independence for as long as possible. However, as the study suggests, there is a growing realisation that caring for dependent elderly people in the community is by no means the economical solution it was envisaged to be — with some evidence to suggest that community care may exceed the cost of residential care. Dementia is one of the most expensive diseases to service adequately in the community, according to the study by Livingstone et al.

It can be assumed generally, in the light of the evidence reviewed here, that increasing demand for good standards of care and availability of services tailored to the needs of people with dementia will increase pressure on available resources and impact directly on health budgets, financial planning and ultimately on service delivery.

1.8 Quality Care: Current Standards and Problems

At present, people with dementia are cared for in a variety of institutional settings: NHS long-term care wards - old age, psychiatric or geriatric - in nursing homes and in other residential care settings. Despite advances in the quality of institutional care and new understandings of the needs of the elderly, the image of institutional care continues to be both a challenge and a problem. Negative perceptions of institutional care have persisted since the 1960's (Goffman 1963; Foucault 1967; Illich 1975).

Unfavourable images are sustained because of the tendency towards institutionalisation and the stereotyping of services in all type of institutions (Wilkin & Hughes 1987, p. 175). Over the past decade in particular, approaches to care of dementing elderly people have been dominated by the person-centred approach, with emphasis on individualised patient care (Kitwood 1997). Failure to adopt an individualised approach to

the person can be interpreted as lack of respect for individuals and their rights, leading to their dis-empowerment, inappropriate control and even abuse (Peace & Kellaher 1997, p. 61). People with dementia are particularly vulnerable because of their dependency on carers and their inability to voice their concerns or to access forms of defence or protection.

To avoid these problems there are clearly identified requirements and strongly recommended practices that are considered fundamental to the provision of a person-centred approach to good quality care. These are supported by a variety of statutory regulations and practical provisions for monitoring standards and controlling the quality of care in various settings.

1.9 Providing Quality Care – Promoting Standards through Policy Changes

Through the Regulation of Care (Scotland) Act 2001, the Scottish Parliament established a body corporate known as the Scottish Commission for the regulation of care, which was given the ‘duty of furthering improvement in the quality of care services in Scotland’.

All care services which had previously been regulated by NHS Boards and local authorities, have since 1st April 2002 come under the regulation requirements of the Care Commission. There are 15 types of care services regulated by the Commission including the following:

- Support services – day care services for adults, care at home services
- Care home services – previously residential care homes for adults and children and nursing homes
- Independent health care – independent hospitals, hospices and clinics
- Adult placement services
- Housing support services (Scottish Executive 2002).

The Care Commission has worked towards the regulation of care services against national care standards in accordance with the requirements of the Regulation of Care (Scotland) Act 2001 and associated regulations (Scottish Executive 2002).

This in effect required all local authority care services to register and to meet the same standards as private and voluntary services. While the Care Commission has responsibility for:

- Regulating care services in Scotland and

- Keeping Scottish Ministers informed about the provision and quality of care services, it is specifically focused on and concerned with the needs of people using care services.

“Regulated Care Services are expected to demonstrate that they promote and enhance the quality of life of service users taking account of the principles of dignity, privacy, choice, safety, realising potential and equality and diversity” (Scottish Executive 2002).

The introduction of the Adults with Incapacity (Scotland) Act 2000 substantially reformed hitherto outdated and inadequate provision for adults with incapacity. The introduction of the Bill was motivated by recognition of the potentially damaging and/or harmful outcomes of existing services for people in need. The Act introduced comprehensive legal reforms to protect the interests of adults (persons of 16 and over) who are not able to make all or some decisions on their own behalf and is based on the principles of autonomy and equity. The new legislation applies to “individuals who are assessed as incapable of acting, communicating or understanding decisions because of mental disorder or an inability to communicate caused by a physical disorder. The main groups to benefit from the provisions of the Act are people with:

- learning disability
- severely acquired brain injury
- severe mental illness

In 2002, the Scottish Executive saw it necessary to commission a two year consultancy for the purpose of exploring issues arising from parts of the Act. The work of the consultancy, which was titled “Learning from Experience”, was specifically focused on matters relating to:

- powers of attorney
- intromission with funds
- intervention and guardianship orders
- monitoring usage and
- undertaking research relating to the Act’s operation

While the findings of the study indicated that the Act works well for adults with incapacity and their carers, the issues raised in the report concerned categories of policy/legislation, procedures and practice, which could require legislative changes to effect improvements or streamlining of procedures.

In addition to the changes in the Adults with Incapacity (Scotland) Act 2000, the Scottish Parliament enhanced its corpus of legislation with the updating of another Act concerned with the well-being of the ill and most disadvantaged in society. The first major

overhaul of mental health law for 40 years occurred with the passing of the Mental Health (Care and Treatment) (Scotland) Act 2003 by the Scottish Parliament for the purpose of ensuring that people with mental health problems could receive effective care and treatment.

The Scottish Executive policy on Mental Health is committed to improving and maintaining the mental well-being of the people in Scotland by working with others, including users, carers, service providers in health and Local Government to:

- “promote attitudes and behaviour in the general public which lead to mental well-being and
- ensure that good quality mental health services are available for everyone that need them at all levels of need”. (Scottish Executive 2003a)

In implementing the Act the Scottish Executive made a commitment to the establishment of a new Mental Health Tribunal that would draw on the expertise of professional and legal services combined with practical experience for the purpose of deciding what would be best for patients.

In addition it was agreed that under the Bill new provisions would ensure that advocacy was available to all persons with mental disorder:

- The Mental Welfare Commission would be strengthened to ensure it had the necessary powers to cater for the protection of people with mental illness and learning disabilities
- A new compulsory treatment order would allow care and treatment to be tailored to the specific needs of individual patients, whether in hospital or in the community and
- Additional safeguards were put in place with regard to the use of certain medical treatments. (Scottish Executive 2003b)

Under the Health and Community Care Policies the Scottish Executive has provided 553 million pounds for the “Free Personal Care” policy since it was introduced in July 2002. The policy contains entitlements and guidance for local authorities and information on the work of the Care Development Group (Scottish Executive 2005c).

In addition the Scottish Executive has developed a working strategy to evaluate the implementation and impact of the free personal and nursing care policy since its introduction in July 2002. It is expected that the working strategy will provide information on the range of services being provided, including their quality and costs and an evaluation of the degree to which they appear to make a difference to the people who avail of the services (Scottish Executive 2005b).

This is yet another aspect of the overall comprehensive changes taking place under the guidance of the Scottish Executive in fulfillment of its commitment to the improvement of the health and well-being of Scottish people. One of its key strategies in achieving this for older people for example was the establishment of Better Outcomes for Older People: Framework for Joint Services. Of specific relevance to this study is Section 6 - Joint Services for People with Dementia and their Carers. The purpose of the joint services was to ensure “that people with dementia and their carers have access to information and advice, receive consistency and continuity of quality care and support, and that services are provided by agencies, which have sound knowledge and expertise of dementia” (Scottish Executive 2005a).

1.10 Managing the Care Needs of Patients with Severe Dementia.

It has already been established earlier in this Chapter that a significant number of hospital admissions are of frail elderly people who suffer from multiple medical conditions compounded by physical and cognitive impairment and coupled with various psychological and social co-morbidities. As discussed, the expansion in drug therapy, medical technology and an ageing population have all been cited as key factors contributing to the ongoing crisis in the costs of health care.

The challenges involved in the practicalities of admitting and managing the care of elderly patients with dementia has been the subject of a number of studies concerned with the management of budgets, bed access and prioritising care provision. Because many nursing homes do not have the capacity in terms of trained nursing staff to provide nursing care for patients with specific and/or multiple medical conditions, hospitals become the place of treatment. In the same way nursing home staff are often reluctant to accept a patient back following a medical procedure or treatment thereby increasing the pressure on hospitals to extend the length-of-stay. The latter contributes to increased care costs and subjects the patient to an extended stay in an environment that is often not well equipped to meet the needs of a person with severe dementia.

Some of the difficulties inherent in caring for patients with dementia in an acute ward setting were summed up by Dr David Kenny, Consultant Geriatrician, as follows:

- most health professionals including nurses miss cognitive impairment in a large number of patients

- relocating a patients to hospital often causes difficulties and serves to aggravate any underlying confusion
- deficient assessment and profiling may be caused by problems of communication
- the confused patients are often subjected to inappropriate research
- the acute ward environment is excessively demanding and basically unsuitable for looking after confused , elderly people
- communication problems are common because of staff failure to recognise deafness and the patients inability to report this
- pre-discharge arrangements are often poor due to too much haste in moving the patients out of hospital because of pressure to make beds available (Kenny 1997)

These are just some of the practicalities and challenges of providing care for patients with severe dementia in a pressurised hospital environment. There are implications for patients in terms of the quality of care they receive and the added burden of confusion arising from unfamiliar care practices. There are also implications for nursing staff who are trained to function in an acute care setting and are ill-equipped in terms of having the necessary time available to establish effective communication with dementia patients as a critical element of care delivery. In addition state registered nurses in general hospital practice usually have limited knowledge and experience of gerontological nursing. Finally, as already explored, the higher activity of patient-stays with reducing length-of-stay may be the key to managing the competing demands for limited resources, but, may be ill-suited to the provision of quality care for confused patients living with dementia. It is against this backdrop that the study directs attention to the provision of quality care for people with severe dementia.

1.11 Conclusion

From the discussion of changes in longevity at the beginning of this Chapter, it was concluded that ageing trends should not only be a concern for us, but should also remind us of the positive potential of continuing advances in social conditions, medical technology and health promotion to assist people to live more active and healthier lives. The Chapter has provided some baseline information on the numbers of people living with dementia and their places of residence and has given an overview of care settings including patient mix and

patient numbers. Projected trends based on reliable prevalence studies have been used to outline expected changes in the foreseeable future. While the Chapter provides an overview of baseline information, it has made no attempt to distinguish between the numbers of people suffering from the different types of dementia. As mentioned earlier, understandings of dementia will be explored more fully in Chapter 2, as will the relationship between severity levels of dementia and care requirements.

Chapter 1 has provided a comprehensive overview of all the most recent and relevant policy changes that have been introduced by the Scottish Executive and actioned by relevant bodies. The extent of the policy changes since 2000 reflects the commitment of the Scottish Executive to fulfil its commitment to the improvement of the health and well-being of the Scottish people.

In recognition of the need to co-ordinate the providers of care, the Commission established a Joint Future Group for the purpose of having services to older people jointly managed and jointly resourced. These are just some of the measures within a range of NHS initiatives, which the Scottish Executive will address as a part of its overall goal to provide high quality readily accessible services to meet the health and social needs of older people in Scotland.

Achieving these objectives in specific terms will mean addressing a range of demographic pressures on demand for long-term care as outlined earlier. While starting from the current levels and patterns of care seems both logical and sensible, it must be recognised that catering for future needs may mean dealing with rising public expectations with regard to the quality and quantity of care available. Rising expectations may also include demands for improvement of material standards for the provision of care, such as accommodation, which will have implications for patterns of expenditure. In short, the issue of providing long-term care for elderly people is a work in progress: it requires the management of many factors including dependency levels of patients, unit costs of care, issue of affordability and service expectations by patients and their families.



CHAPTER 2:

Understanding Dementia

2.1 Introduction

Initially it may seem that dementia is both easy to define and to understand. However, it is still the case, that only a doctor can make a diagnosis of dementia — following thorough psychological and medical examinations. Such examinations may find a psychological or medical cause for the person's behaviour. If for example, excessive alcohol consumption or vitamin deficiency is found to be the cause of the condition, then something can be done to reverse the situation with treatment. This approach, which considers dementia in terms of its being a disease, has its roots in the medical model, which appears to be widely accepted and understood.

Over the past decade, the medical approach to dementia has come under scrutiny and has often been harshly criticised by those who believe that 'there are major gaps in the evidence for the validity of this approach' (Chester & Bender 1999, p. 79). While it is widely accepted that dementia has some physical causes, according to some authorities, it is socially constructed. From this standpoint, what we call dementia is the result of the ways in which older people have been treated by those who care for them and by society at large (Redfern & Ross 1999, p. 525). These ideas have their roots in the work of social psychologists and sociologists who are primarily concerned with understanding and interpreting the intentions and behaviour of people. This shift toward the recognition of the psychological aspect of dementia care, has been promoted by Gubrium (1986), Fox (1989), and others, but particularly influenced by the work of Tom Kitwood (1997a) — which gave rise to what has come to be known as the 'person-centred approach to care'.

It is, however, critically important to avoid the tendency to polarise these models, as many theorists do, and attempt, rather, to appreciate more fully the uniqueness of each model, the points of difference between them, and the issues emerging that are central to ongoing discussion on dementia care. Based on this aim, the discussion that follows will focus on:

- the medical model approach to dementia care
- how and why the model is seen to be problematic
- issues of medical practice and the resolution of ethical concerns inherent in approaches to care

- the development of the psychosocial approach to dementia care, giving specific attention to its core concept - the person-centred approach
- the two models which will be contrasted and compared
- how the models might be perceived as interdependent and complementary.

2.2 Defining Dementia - A Medical Model Perspective

Like most people I know, I have engaged in conversations about dementia over the years and remarked on its regrettable impact on people who struggle to live with it. However, until commencing this research I had assumed a popular understanding of dementia and had not appreciated the difficulties in actually defining it. A search of the literature indicated that dementia is not a diagnosis (Fraser 1987, p. 1), a disease (Stokes & Goudie 1999, p. 16), an illness (Goldsmith 1998, p. 6), or a disorder (Jones & Miesen 1996, p. 9).

These words: 'diagnosis', 'disease', 'illness' and 'disorder', all have distinct meanings yet are often used interchangeably to refer to a person's state of health or sense of well-being. However, it is the fact that so many writers choose to approach the process of defining dementia in this way - by first stating what it is not - that is both peculiar and revealing. Saying what dementia 'is not' conveys a sense of correcting some 'alternatively' held views or theories, or perhaps some 'erroneous' or 'damaging' perspectives on dementia. While these statements fail to inform the reader about dementia, the approach does perhaps reveal something of the complexity of the topic, and the lack or absence of a unified understanding or approach to dementia.

The picture does not become much clearer initially, as theorists proceed to define dementia as: a syndrome or group of symptoms, which can be manifested in a variety of combinations (Jacques & Jackson 2000, p. 2; Jones & Miesen 1996, p. 9; Goldsmith 1998, p. 6); a blanket term used to refer to a variety or group of conditions (Downs & Marshall 1997, p. i; Fraser 1987, p. i; Holden & Woods 1995, p. 9); or 'a set of signs and symptoms indicating a need for further investigations' (Stokes & Goudie 1999, p. 16). Despite the fact that dementia is considered an evolving concept (Adams & Clarke 1999, p. 6) which continues to change over time, and that dementia definitions can generally be classified as descriptive or operational (Redfern & Ross 1999, p. 527), the following is regarded as definitive:

Dementia is the global impairment of higher cortical functions, including memory, the capacity to solve the problems of day-to-day living, the correct use of social skills and control of emotional reactions, in the absence of gross 'clouding of consciousness'. The condition is often irreversible and progressive. (WHO 1986)

This definition, recognised by WHO and the Royal College of Physicians, uses unambiguous medical language to define disturbances collectively referred to as dementia. The definition has its roots in a medical paradigm, based on the belief that changes in the brain cause behavioural changes, resulting in a series of stages which become progressively worse. Within this comprehensive definition the clinical signs of dementia viz. *global impairment of higher cortical functions* are said to affect the memory in terms of making it difficult to assimilate and retain information, affecting both short and long-term memory. Orientation is also affected as the person experiences problems identifying time, places and people. At an intellectual level the person has increasing difficulty comprehending what is going on, thinking slows down and judgement and problem-solving abilities are impaired. Other indicators of the condition are deteriorating speech patterns, inappropriate and often antisocial behaviour including wandering, aggression and incontinence, as well as mood changes, depression, agitation and a neglect of self-monitoring. All of these elements are said to reflect neurological impairment, which is a disorder of the central nervous system (Norman & Redfern 1997, p. 185; Parker & Penhale 1998, p. 11).

Memory loss tends to be the first thing people invariably think of and associate with dementia. As indicated above, there are many other features to dementia which is a progressive condition that changes and develops over time. The collection of symptoms outlined above, indicate that a physical deterioration occurs in the brain, often at a slow pace, but not necessarily in a uniform way. However, the clinical features described are general, and tend to be displayed differently, and in different combinations, from person to person. Given the fact that the individual's memory, intellect and ability to communicate deteriorate, the process of diagnosing dementia is dependent upon observed behaviours such as those outlined above. Given this intellectual impairment, it is difficult to get a clear idea of how the person himself is experiencing life with dementia.

2.3 The Medical Model is Problematic

The WHO definition of dementia is widely recognised and supported, particularly by the medical profession (Gelder, Gath & Mayou 1989; Lishman 1987). The medical model,

sometimes referred to as the organic model or 'standard paradigm' (Kitwood 1990), bases its definition around the neurological impairment of the brain, affecting the person's intellectual, linguistic and cognitive functioning. This particular approach, according to Parker and Penhale (1998), placed dementia firmly within the province of the medical profession in the sense that a correct diagnosis of the disease is crucial in order to prescribe and treat the patient. The fact that the medical definition of dementia appears to be endorsed by nursing professionals (Jones & Norman), social work theorists (e.g. Mary Marshall) (Norman 1982), and dementia care professionals (Marshall 1990), is of concern to Parker and Penhale and to some social constructionists (or deconstructionists) (Harding & Palfrey 1997) and psychosocial theorists such as Tom Kitwood, as will become evident later.

Their concern arises from the fact that the medical model describes dementia as a disease and fails to recognise that it is different for each individual — being influenced by life experience, personality, coping skills, living situations, beliefs and values (Parker & Penhale 1998, p. 16). Another concern arises from the fact that the medical profession can only speak confidently about the patient's illness by looking at the brain after death, which may be helpful in research but less so in treatment (Murphy 1986). However, what seems to be at the heart of the tension between the medical approach and the social approach to dementia care, is the tendency of the medical model to be illness-focused rather than person-focused, and to be cure-focused rather than to focus on care. From the earliest days of the profession, doctors have valued 'cure' as the ultimate goal of the medical model. We live in an age and in a society that is willing to invest considerable resources towards finding cures for cancer, AIDS and other diseases. We want the cure to be effected quickly and expect it to involve the use of drugs ['magic bullets'] or state-of-the-art technology. Perhaps more than ever before, society and the medical profession have the same goal - 'to find a cure' for dementia.

But, elderly sick, dementing people do not conform easily to the standard medical model (Isaacs 1981). One single diagnosis is not always possible as the older person usually presents with multiple disease manifestations, complicated by the effects of the ageing process. In the same way, patients suffering from dementia present with a complex combination of clinical problems and no two people will necessarily present with the same combination of symptoms. Despite these problems, it must be admitted that research in the biomedical sciences is making a contribution to our understanding of dementia and some progress is being made in its pharmacological treatment. Drug treatments for dementia can broadly be grouped into four categories, viz:

- a) treatments for behaviour symptoms such as agitation and depression,

- b) treatments for primary symptoms - memory, orientation,
- c) treatments to slow the rate of decline and,
- d) treatments to delay the time of onset of the disease (Norman 1999, p. 548).

Norman goes on to make the point that there may be some overlap between the actions of the drugs and that, as yet, no single agent has been found to be significantly effective. The general practice in pharmacological treatment is towards the use of combinations of drugs, to provide treatment packages suited to the needs of an individual patient at any given stage. Nevertheless, the response to the individual treatment packages may vary from person to person, just as the experience of the disease, or the display of clinical features may vary as mentioned above. The fact that the risks of such treatments may outweigh any benefits is of concern and requires careful monitoring (Redfern & Ross 1999, p. 548).

Pharmacological treatment is a key feature of the medical model, which primarily defines dementia as a 'disease of the brain'. This approach to and understanding of dementia has implications for the patterns of care provided, and for how the patient is understood, perceived and treated as a person. The main features of the medical model of dementia are outlined in Table 2.1 below and many of the implications for care management are summarised.

Table 2.1: The Standard Paradigm of Dementia Care (Chester & Bender 1999, p. 68)

| | Main Features | Implications for care management | Implications for the internal world of sufferer |
|-------------------------------|---|--|--|
| Causation | Only neurological changes are of interest. Cell destruction due to plaques, tangles & vascular destruction. Neurological changes due to biochemical & genetic factors | The disease is seen as progressive & degenerative, so once established little can be done to affect prognosis. The aim of care is essentially to make life as tolerable as possible | The internal world is of no consequence to disease process, so it is seen as being of little or no relevance to process of care. |
| Psychological features | Brain damage, especially alteration in cognitive functioning, personality & memory, is equated with destruction of mind. Dementia is seen as the death of the person. | Emphasis on diagnosis - a need for the assessment of cognitive functioning in order to distinguish between dementias and pseudodementias. The individual is seen as unable to make decisions about his own care. | The internal world of the person with dementia lacks validity, due to the damage to their brain. All necessary decisions should be agreed between professionals & relatives/carers |
| Symptomatology | Many, varied & usually strongly negative. Includes confusion, wandering, disorientation & aggression | Assessment of problematic behaviours. Medication and behavioural management, advice & support to carers | Individual has little meaningful (conscious) control over his actions. The only valid role is that of a 'patient'. Relationships are invalidated |

Chester and Bender are clinical psychologists and their summary of the weaknesses of the standard paradigm or medical model, as outlined in the table above, is fairly representative of the views of proponents of the psychosocial model of dementia care. The medical profession is credited with the re-creation of Alzheimer's Disease, and the facilitation of significant funding being directed towards biomedical research. However, proponents of the psychosocial model in particular, believe the medical approach functions within a very constricted explanatory framework that is primarily concerned with what is happening in the person's brain, namely, neurological changes. In the table above, neurological changes resulting from biomedical and genetic factors are considered to be the main cause of dementia. The disease is perceived to be irreversible. However, some elements can now be managed more effectively with medication, and this has obvious implications for managers.

It is the claim by Chester and Bender, that the internal world of the dementia patient is of no consequence in the medical model, that should be of prime concern. The claim in effect means that a person with dementia is being treated as a non-person. As suggested in the table above, the subjective experience of the person is ignored, or considered of no consequence, and assessment is focused primarily on memory. Within this model all responsibility and autonomy are removed from the patient and decision-making is confined to, or shared between, professionals and caregivers only. This by default implies that the carer's role is simplified to that of taking responsibility for, or control over, the person with dementia. In addition, medication is presented as the critical means for the management of presenting symptoms or behaviour problems.

The Chester and Bender criticisms of the medical model are not new. Medical practice is based on a scientific approach and is primarily concerned with diagnosis. Doctors concentrate mainly on what is causing the illness; the nature of the disease; and prescribing treatment or medication to eliminate or manage problems (Abbott & Meerabeau 1998, p. 219). Traditionally, the task of diagnosing has been the domain of the doctor as the expert and the management of care plans based on the diagnosis has been the domain of the nursing profession. While the boundaries between nursing and medicine can at times be somewhat fluid — e.g. where in a ward situation, nurses undertake delegated tasks such as administration of intravenous antibiotics — doctors are unequivocal about their responsibility for activities that come closer to the focal task of medicine (Abbott & Meerabeau 1998, p. 219). It does seem that Chester and Bender do not appear to have given due consideration to this point and, as a result, have confused roles and practices to a degree.

The Chester and Bender claim, that the doctor fails to give credence to what the person with dementia may have to contribute to the diagnosis, is true to some extent. This is so because the doctor reaches a diagnosis based on physical examination and tests and a specific scientific body of knowledge, acquired through professional training and ongoing research, of which the patient has possibly little or no understanding. It is however, perhaps somewhat inaccurate to say the doctor does not involve the patient - traditionally doctors have tended to be both methodical and thorough in developing a profile of the patient's history - medical and social - based on questions answered by the patient or by a next of kin. It must be recognised of course that this very process can in itself be problematic - the issue of iatrogenic insult will be discussed in the next chapter.

2.4 Medical Practice and Ethical Responses

The aim here is not to defend the medical model or to rationalise away behaviour that might otherwise be described as unacceptable – e.g. that of treating the patient as a non-person and showing scant regard for patient autonomy, by failing to involve them in the process of diagnosis. What is being suggested however, is that it is necessary to explore the doctor-patient relationship more closely to identify and understand what motivates the doctor to assume certain approaches to patient care. To expose the complexity of certain arguments and decisions that might otherwise appear to be fairly obvious or straightforward, a case study will be used to focus attention on the complex nature of an issue which doctors face on a regular basis, namely: *whether or not to tell the patient they have dementia*.

2.4.1 A Son's Request for Nondisclosure

Mr Johnson, a man in his late sixties, is brought to his physician by his son, who is concerned about his father's apparent problems in interpreting and dealing with what used to be normal day-to-day activities. He worries that his father may have Alzheimer's Disease, but he asks the physician not to tell his father if Alzheimer's Disease is confirmed as the diagnosis. After the appropriate test, the physician believes that she has a firm diagnosis of Alzheimer's Disease and discusses with a nurse and a social worker the son's "impassioned plea" not to tell his father the diagnosis. The nurse notes that a strong consensus has developed over the last twenty-five years about disclosing the diagnosis of cancer to patients and wonders whether the same reasoning applies to disclosure [of their diagnosis] to patients with Alzheimer's Disease.

The physician responds that "many of the arguments that support telling the patient with cancer assume the relative accuracy of diagnosis, an

array of therapeutic options, a predictable natural history, and a fully competent patient." She is not sure that these arguments apply to patients with Alzheimer's Disease because the diagnosis is made on the basis of clinical criteria and diagnostic algorithms [documented through autopsies to be as high as 92%], the prognosis is "unusually imprecise", life expectancy varies greatly, therapeutic options are limited and patients with Alzheimer's Disease "inevitably have an erosion of decision-making capacity and competency" and may also have limited coping mechanisms.

The social worker adds that, although there is empirical evidence that most patients now want to know if they have cancer, there is less evidence about the preferences of patients with Alzheimer's Disease. Nevertheless, the nurse responds, "it is important to maximise individual autonomy wherever possible. We can be truthful with our patients about what we think is happening and our degree of certainty, whatever it is. Mr Johnson may be able to make an advance directive about treatment and nontreatment. At the very least, he may be able to express his feelings." "But wait", the physician responds. "Mr Johnson will lose his ability to change his mind once he loses his ability to make decisions." "That's true", the nurse agrees, "but still the best indication we could have of what he would want under those circumstances would be his advance directive." The physician, nurse and social worker agree to discuss the case tomorrow before deciding what to do. (Beauchamp & Childress 1994, p. 259)

Numerous ethical issues emerge from the Mr Johnson case. These include respect for patient autonomy, appropriate information disclosure, familial rights and the scope for responsible decision-making. The management and resolution of the issues arising are fundamental to ethical practice and are primarily centred on the principles of autonomy (respecting the decision-making capacity of a person), nonmaleficence (to avoid causing harm) and beneficence (to provide benefits and to balance benefits against risks and costs) (Beauchamp & Childress 1994, p. 38). In the Mr Johnson scenario these three principles are directly involved and underlie the moral problems faced by health care teams and individual nurses and doctors. However, they are also involved in the on-going care of dementia patients because the obligations generated by the principles are fundamental to their care.

For example, in the nurse's view, the patient has a right to know the results of the tests so that he can make advance directives before his condition deteriorates any further. The nurse is clearly operating out of respect for the patient's autonomy and would also appear to be acting in a responsibly caring way by suggesting that the patient make advanced directives while able to do so — a requirement of beneficence. On the other hand, the doctor's perspective that the patient will lose his ability to change his mind once he loses his ability to make decisions may lead him to a

different conclusion. The doctor may be of the opinion that advance directives are not significant, (even though it is one of the few ways of knowing the patient's wishes when they can no longer speak for themselves) because the patient's condition will deteriorate to a point where they cannot decide, and it is incumbent on him to exercise a duty of care on behalf of the patient from the start.

Is this a case of paternalism on behalf of the doctor? The doctor in this case faces a dilemma, because of the conflicting demands of the principles of autonomy and beneficence. He is constrained by the lack of certainty in the diagnosis, and also by the likelihood of the patient responding adversely to the disclosure—in which case the principle of non-maleficence would apply, i.e. not to harm the patient or cause them further distress. It is not an issue that can be easily resolved but in fact, as the situation changes, the balance may shift from an emphasis on promoting the patient's autonomy, to taking responsibility to exercise a duty of care on their behalf. However, the central issue in the Mr Johnson case was the request by his son for 'nondisclosure of information'. This raises quite different and separate issues, relating to the rights of relatives, or significant others, to determine the ground-rules for dealing with the patient. As in the dialogue in the case of Mr Johnson, there are no, easy or clear-cut answers in such situations and the debate might have to continue along with changes in Mr Johnson's condition as these will impact on the nature of the relationship between the client's rights and the responsibilities of the health carers.

In a 1979 survey, Dennis, Novack and several colleagues sought to elicit physicians' attitudes towards using deception to resolve difficult ethical problems. The physicians identified the four most frequent factors, which are considered in the decision to tell or not to tell the patient the diagnosis. These factors are age, relatives' wishes regarding disclosure to the patient, emotional stability and intelligence (Novack et al 1989). In the case of Mr Johnson who was in his late sixties, it is likely that at least 56% of physicians according to the Novack study would take his age into account, when deciding to disclose information regarding his diagnosis. There is little to suggest that age on its own should be a key factor. In fact, an older person, as a result of years of experience of facing difficult situations, might actually be more resilient than a younger person.

In a discussion on possible ways of communicating with people with dementia, Mary Marshall (1996, p. 29) observed that it is not easy for doctors to decide, 'how, when, and with whom to share the diagnosis and they often fall back on their own preferences'. She goes on to suggest that it would seem good practice to assume that

the person with dementia wants some information, especially in the early stages of the disease, and that information should be given in a step by step process depending on the receptivity of the patient. Sharing the diagnosis is thought to be the responsibility of the person making the diagnosis - the hospital specialist or the G P. Some specialists and doctors prefer to share the diagnosis with the whole family, with the person with dementia present. This approach is based on the belief that it is treating the patient as an adult, and that it makes relationships more straightforward as the disease progresses (Marshall 1996, p. 48). Some doctors prefer to tell the carer and the patient separately while others decide to share the information with the carer only.

Returning to the Mr Johnson case, 51% of doctors according to the Novack survey would be willing to respect the son's request and would not share the diagnosis with Mr Johnson. Tom Beauchamp and James Childress (1994, p. 388) do not agree with this standpoint, believing that familial preferences are often prejudicial to patient autonomy and are unjustifiably influential in clinicians' decisions about disclosure of their diagnosis and prognosis to patients. Beauchamp and Childress are aware that critics of their position argue that next of kin can actually help the doctor determine whether or not the patient can be regarded as autonomous. Autonomy is broadly defined as follows:

Self-government under principles, ideals or standards that are endorsed...by reason. Other things being equal, the more rational and psychologically stable the agent's (patient's) endorsement of the principles, ideals or standards, and the greater the extent to which the agent's conduct is under their control, the more autonomous the agent is. (Audo 1997, p. 208)

Determining patient autonomy is recognised by Beauchamp and Childress as critically important, albeit with the assistance of family. However, they do believe this begs the question - *by what right does a physician initially disclose information to a family member without the patient's consent?* (Beauchamp & Childress 1994, p. 399) They go on to make the point that the autonomous patient has the moral right to veto familial involvement, and that truthfulness and honesty - respect for patient autonomy – should be a primary rule or virtue in the doctor's moral orientation. On what basis then can the doctor justify first disclosing information to family members, even when the family requests such information, if it means disregarding or overriding the autonomy of the patient? Beauchamp and Childress are in agreement with Marshall that good practice demands disclosure of information to the patient at the outset, and throughout the illness as the patient wishes.

In the case of Mr Johnson, who may be 'non-autonomous or doubtfully autonomous', Beauchamp and Childress (1994, p. 399) are of the opinion that doctors 'may have obligations to disclose appropriate diagnostic information to the patient even when family members - in this case Mr Johnson's son - request nondisclosure'. On the other hand, the amount of information that is, or should be, disclosed to the patient 'is also a matter of sensible and responsible judgement, according to Thompson et al (1996, p. 79). This view is based on the reasoning that refusal to disclose critical information can actually deprive the person of the knowledge and insight required to make important decisions and plans for their future — a point made by the nurse in the Mr Johnson case. The nurse was clearly of the opinion that withholding information from the patient would be to keep the patient in ignorance, and show disregard for patient autonomy. The nurse argues that a more caring, responsible and perhaps professional approach would be to share the information with the patient. The nurse's stance in the Johnson case, would appear to be supported by Thompson et al (1996, p. 80), in their conclusion that withholding information from a patient encourages a state of dependency and can even be a means of maintaining control over the patient, while failing to assist the patient towards autonomy.

Alan Jacques and Graham Jackson, both consultants in old age psychiatry, outline several factors that a doctor is likely to take into account regarding sharing the diagnosis. For example, a diagnosis should not be given until one is sure that it is a correct diagnosis. This in effect means that an early diagnosis, however desirable, may not be possible — since the presenting symptoms may have to be observed for a period of time, and each one tested, by a process of eliminating other possible causes of patient confusion e.g. infection or nutritional deficiencies. The doctor must consider the likely impact on the person (Jacques & Jackson 2000, p. 215-216). According to Jacques and Jackson, denial is a common reaction. On the other hand the person may react by becoming depressed and pessimistic. This draws attention to two of the four clusters of basic principles identified by Beauchamp and Childress as central to biomedical ethics - beneficence and non-maleficence. These two principles have throughout the history of medical ethics been viewed as justifying the adoption of a protective role towards the patient. For example, if disclosing information as in the case of Mr Johnson were to cause harm, then medical ethics oblige the doctor not to cause harm and, therefore, not to share the information.

The doctor in the Mr Johnson case is faced with a dilemma which arises from a conflict based on the demands of beneficence. As Jacques and Jackson and Marshall

point out, it is now common practice to inform a patient of a diagnosis, but obviously based on having a reliable diagnosis and the competency level of the patient. But, in the case of a person with dementia, the act of informing may adversely affect the patient's ability to cope and may ultimately result in harm to him. The situation also raises the issue of patient autonomy versus professional autonomy - the rights of the doctor or physician to make a clinical decision. The issue appears to be - does the risk to the patient outweigh the possible benefits? If yes, then the doctor, according to Beauchamp and Childress (1994, p. 283), is obliged to exercise a protective duty of care toward the patient, to prevent greater harm.

2.5 Conflict between principles of biomedical ethics

The majority of the moral dilemmas faced by doctors and nurses appear to stem from conflict between obligations generated by the different demands of the principles identified above. For example, honesty, openness and truth telling are behaviours that are fundamental to the principle of respect for persons. If a doctor or nurse feels that revealing a diagnosis to a dementing elderly person will only add to their suffering and therefore refrains from giving this information, they can be accused of lacking in respect for the autonomy of the patient. For example, Rowson writes:

(If) someone lies to you, he is reducing your capacity to understand your surroundings; and since this capacity is a valuable part of you as a person, he is thus failing to respect you as a person... (1990, p. 15)

The point here is that an autonomous person needs to be given critical information in order to exercise choice, which is basic to one's ability to engage in any rational decision-making. On the other hand, are there situations when exercise of a protective duty of care could or should take priority over patient autonomy? For example, when an elderly person does not want to get out of bed, should the nurse insist, given that keeping the patient mobile is in his/her best interest? According to Edwards (1996, p. 94), 'it may be claimed that any actions which seek to override the autonomy of another moral agent stand in need of justification'. But in this case the patient's mobility might be put at risk without exercise so this would, perhaps, justify the nurse in over-riding the patient's wishes.

In effect, all medical or nursing interventions may involve compromise of the patient's rights to autonomy and privacy. Finding the balance between giving full explanations of what is being done and why - as an essential element of the agent remaining free - and judging what the patient needs to know and is capable of understanding, is a quandary for

many health professionals on a daily basis. Will the patient be further burdened by an abundance of information and choices between different treatments, the implications of which they do not feel they fully understand. While the legal aspect of consent to treatment is based on competence, what if the person is temporarily too ill or exhausted to communicate in a competent manner? In such circumstances there can be a clash of principles in terms of deciding: who should give consent; who should make judgements about the competency of the person or provide information; and who should decide on the content of the information given (Tschudin 1999, pp. 17-18).

There are numerous other dilemmas faced by nurses and doctors on a day-to-day basis where decisions have to be made, and meeting the expectations of ethical principles becomes a balancing act, with few clear-cut answers. The issue of whether the principle of autonomy takes precedence over the other principles is an ongoing debate in medical ethics. There are those who say that seeking consent from a patient, respecting the patient's privacy or respecting confidentiality are all elements of respect for the principle of autonomy in the doctor/nurse-patient relationship. Conversely, there are those who would argue that such obligations are practical expressions of the principle of beneficence. However, ethics, like nursing is a practical science (Tschudin 1999, pp. 1, 85-87) which demands that decisions be made based on informed judgements about critical situations in the light of ethical principles and experience.

According to Beauchamp and Childress (1994, p. 272) the physician's main responsibility is to act in the best interest of the patient in terms of medical benefit; it is not to promote autonomous decision-making. They go on to claim that arguments relating to patient's rights and autonomy have become so influential, that it is actually difficult to identify clear models of medical beneficence. It is not clear why this should be so. For example, if a patient is seriously injured and unconscious following a road traffic accident, it would be absurd for a medical practitioner not to act to save the persons' life, whatever it takes. However, according to Beauchamp and Childress (1994, p. 272) there are no absolute moral principles from which medical practice must flow other than the injunction to act in the best interests of the patient.

This in effect means that there may be circumstances in which the doctor in his/her best judgement and in the best interests of the patient will have to override the patient's judgement. However, it would seem that the issue of medical and nursing practice is not about one principle overriding another, or of making either an absolute, because no such authority rests with the nurse or the doctor. It would appear rather that beneficence is a

primary obligation and goal in medical and nursing practice, and that respect for the patient's autonomy sets limits in terms of how that goal is pursued.

2.6 Changing Perspectives on Dementia

2.6.1 The Psychosocial approach to Dementia.

As already indicated, dementia research and care have been dominated by the medical approach. Over the last decade however, there have been attempts to approach dementia from different perspectives - shifting away from a narrow focus on the brain and neurological impairment to recognition of the importance of the social world and the lifetime experiences of the dementia sufferer.

Tom Kitwood, a social psychologist, is considered to be the foremost advocate of this alternative framework for understanding dementia (Chester & Bender 2000, p. 80; Harding & Palfrey 1997, p. 59; Goldsmith 1998, p. 24). He has exposed the flimsiness of the medical evidence supporting the traditionally accepted definition of dementia, based primarily on neurological impairment, (and identified above as the medical model or standard paradigm). Kitwood considered evidence from post-mortem studies and noted that some people, who had dementia, displayed very little neurological damage and that even in cases of severe brain damage, people had remained mentally alert (Parker & Penhale 1998, p. 20). He argued that the relationship between the brain, mind and dementia is obscure, and the change in brain tissue found after death in people suffering from Alzheimer's type dementia is not primarily caused by the dementia (Harding & Palrey 1997, p. 50).

Kitwood's (1997b) main contention is that there are problems or difficulties in seeing a linear causal relationship between brain pathology and dementia. He is not denying the contribution of medicine but argues that 'the dementing process should be viewed as the outcome of a dialectical interplay between two tendencies: neurological impairment and a contribution of personal psychology and social psychology (Norman & Redfern 1997, p. 189). His main objection to the medical model is that it fails to recognise the dementia sufferer as a social being. He argues that the person's dementia must be considered in relation to their personality, biography, physical health, neurological impairment and social psychology (Kitwood 1993). In support of Kitwood's concept, Malcolm Goldsmith (1998, p. 24) adds 'all these factors combine to make a person who they are, and to concentrate on one of the factors only, without

proper regard for the others, is to treat the person as less than a whole person'. Based on psycho-biographical accounts from relatives of dementing people, Kitwood (1993) proposed that certain traumatic life experiences or events such as bereavement, or a major physical illness, may contribute to the precipitation of dementia.

Kitwood and Bredin (1992) argue that once someone is diagnosed as having dementia there is a tendency to focus on their deficits and on how they are damaged, which can lead to disempowerment, intimidation and invalidation of the person, because it ignores or overlooks the dementia sufferer. This, Kitwood (1993) calls the 'malignant social psychology' and stresses the need to recognise and respond to the enduring 'personhood' of the person with dementia.

2.6.2 The Concept of 'Personhood'

It is perhaps not so surprising that a 'person-centred' approach is now central to debate on dementia care given the spreading influence of 'person-centred' principles derived from understandings of 'personhood' in many fields of human thought and activity throughout the 20th Century. For example philosophers such as Jean Paul Satre in his work on *Existentialism and Humanism* (1948), Paul Tournier in *The Meaning of the Person* (1974) and in more recent times Xavier Monasterio in *To be Human* (1985) and Charles Taylor in his book on *The Sources of the Self* (1989) all have profoundly influenced the discussion on and understanding of personhood.

First articulated by the US psychologist and therapist Carl Rogers (1959) those ideas, variously described as 'person-centred', 'Rogerian', 'humanistic' and 'phenomenological', have permeated way beyond the field of mental health in which they originally grew: education, business consultancy, staff supervision and training, and international relations have all been affected, as has every conceivable speciality and discipline within the field of mental health (Morton 1997, p. 371).

The concept of personhood, which is central to Kitwood's approach to dementia, can be found in three main types of discourse: 'those of transcendence, those of ethics and those of social psychology' (Kitwood 1997, p. 8). Kitwood goes on to explain that the term is used and defined differently in each of the three contexts, but does share a core meaning that provides a basic conceptual unity. In his observation, Kitwood points to the fact that in most cultures 'being-in-itself' is sacred and life is revered. The major religions of the world reflect something of this in their doctrines, scriptures and/or rituals. In the same way non-theistic religions or recognised spiritual paths believe in an essential goodness or perfection that is always present and can be

reached or discovered through personal enlightenment. For secular humanists the welfare of people and the understanding of self is fundamental to meaning in life.

In the main ethical discourses of western philosophy, the absolute value of each person is a key theme, which obligates us to treat each person with respect, and never as a means to an end. In addition, the term personhood has a somewhat flexible and varied use within the discipline of social psychology, being primarily associated with self-esteem and the interaction between individuals and groups, reality orientation or the intensive use of sedatives. Again the ethical implications of these practices will be explored more fully in the next chapter.

To more fully appreciate Kitwood's understanding of personhood and the 'person in relationship' it is necessary to reflect briefly on the source of his inspiration. He draws on the work of Martin Buber, whose books *I and Thou*, and *Between Man and Man*, written in the aftermath of the First World War, have had considerable influence on the contemporary concept of personhood. Buber's work centres on a way of being in the world - a way of living relationships. His 'I - Thou' mode implies going out towards others; self-disclosure; spontaneity - a journey into uncharted territory, which may involve anxiety or even suffering ... 'all real living is meeting' ... the ideas to be associated with this are openness, tenderness, presence (present-ness), awareness. More than any of these, the word that captures the essence of such meetings is 'grace' (Kitwood 1997, pp. 10-11). Grace, according to Kitwood, implies and is to be interpreted as favour or gift.

For Kitwood, Buber's work links the three types of discourse in which the concept of personhood is found:

- | | |
|---------------------|--|
| Transcendental - | human relationships are the only valid route to what some would describe as an encounter with the divine |
| Ethical - | strong emphasis on the value of the person gives absolute priority to engagement and commitment |
| Social psychology - | foundation for an empirical inquiry in which the human being is treated as a person rather than as an object |

For Kitwood, personhood must be understood in *relational* terms. This is critical to understanding dementia and must underpin approaches to care. 'It is a standing or status that is bestowed upon one human being, by another, in the context of relationship and social being. It implies recognition, respect and trust' (Kitwood 1997, p. 8). For Kitwood, his approach is based on an ethic that contains three central

ideas: respect for persons, 'I-Thou' relating and moral solidarity - a recognition of the essential unity of all human beings' (Kitwood 1997, p. 100).

He believes that the 'I-Thou' form of meeting is possible even when cognitive impairment is very severe and adds:

There is, however, a very sombre point to consider about contemporary practice. It is that a man or woman could be given the most accurate diagnosis, subjected to the most thorough assessment, provided with a highly detailed care plan and given a place in the most pleasant surroundings - without any meeting of the 'I-Thou' kind ever having taken place. (Kitwood 1997, p. 12)

This quote foreshadows the work of the next chapter, which will focus on the implications of Kitwood's approach, by examining many of the current practices in care delivery.

2.7 Characteristics and Criticisms of Medical and Psychosocial Models

So far, we have seen that the psychosocial model differs in a number of key ways from the medical approach to dementia. For example, Kitwood's research findings into post-mortem studies found no significant link between dementia and neurological impairment, thus casting doubt on the traditionally accepted link between the development of dementia and neurological changes in the brain. The psychosocial model places significant emphasis on the impact of the dementia sufferer's social world, while this appears to be of little or no consequence in the traditional medical approach. There is also a tendency in the medical approach for assessment to focus on the abilities the person has lost or on how they are damaged, while the psychosocial approach tends to focus and work with what capabilities the person has remaining.

In addition, as discussed above, the diagnosis of dementia according to the medical model can be unreliable, with devastating results. These are some of the differences identified by Kitwood in his work on 'the new culture of dementia' - a term which captures changes in beliefs and attitudes towards dementia and in the organisation of care for dementing people (Redfern & Ross 1999, p. 525). Kitwood contrasts 'the new culture' with 'the old culture of dementia' - the latter being a representation of the medical model. In the table below Kitwood identifies the contrasting elements of both cultures, and I have adapted the model by way of adding comments as a critique of the Kitwood framework.

Table 2.2: Two cultures of dementia care (Kitwood 1997a, p. 136)

| | Old Culture | New Culture | Comment |
|-------------------------------------|---|--|---|
| General view of dementia | The primary degenerative dementias are devastating diseases of the central nervous system, in which personality and identity are progressively destroyed. | Dementing illnesses should be seen, primarily, as forms of disability. How a person is affected depends crucially on the quality of care. | <i>Irrespective of the quality of care delivered, there is considerable evidence to support the 'old culture' claim that the impact of the disease on the person is devastating, becoming progressively worse over time.</i> |
| Ultimate source of knowledge | In relation to dementia, the people who possess the most reliable, valid and relevant knowledge are the doctors and the brain scientists. We should defer to them | In relation to dementia, the people who possess the most reliable, valid and relevant knowledge are skilled and insightful practitioners of care. | <i>A multidisciplinary approach to dementia care is likely to be more effective. There should be no room for professional jealousies or 'protection of territory'</i> |
| Emphasis for research | There is not much that we can do positively for a person with dementia, until the medical breakthroughs come. Hence much more biomedical research is urgently needed. | There is a great deal that we can do now, through the amplification of human insight and skill. This is the most urgent matter for research | <i>Following the example of cancer research, answers to dementia should be pursued through research in the fields of medicine, psychiatry and the social sciences.</i> |
| What caring entails | Care is concerned primarily with such matters as providing a safe environment, meeting basic needs (foods, clothing, toileting, warmth, cleanliness, adequate sleep, etc), and giving physical care in a competent way. | Care is concerned primarily with the maintenance and enhancement of personhood. Providing a safe environment, meeting basic needs and giving physical care are all essential, but only part of the care of the whole person. | <i>Maslow's hierarchy of needs (Rearson, Vaughan & Fitzgerald 1998, p. 212-213) would suggest that providing for the basic needs of the person in the form of food and shelter take priority over ensuring the self-actualisation of the person</i> |
| Priorities for understanding | It is important to have a clear and accurate understanding of a person's impairments, especially those of cognition. The course of a dementing illness can be charted in terms of stages of decline. | It is important to have a clear and accurate understanding of a person's abilities, tastes, interests, values, forms of spirituality. There are as many manifestations of dementia as there are persons with dementia. | <i>Old culture, concerned to exercise a protective duty of care, to ensure that the person does not harm self (beneficence/ nonmaleficence), the new culture, focussed on respect for the person's rights and what is required to help the person (Respect for Persons & Beneficence)</i> |
| Problem behaviours | When a person shows problem behaviours, these must be managed skilfully and efficiently. | All so-called problem behaviours should be viewed, primarily, as attempts at communication, related to need. It is necessary to seek to understand the message, and so to engage with the need that is not being met. | <i>If a person is behaving violently, the priority might be to skilfully remove the patient to a safe environment, away from the scene of the violence, after which it may be possible to assess what motivated the behaviour</i> |

| | Old Culture | New Culture | Comment |
|-------------------------|---|---|---|
| Carer's feelings | In the process of care the key thing is to set aside our own concerns, feelings, vulnerabilities, etc., and get on with the job in a sensible, effective way. | In the process of care the key thing is to be in touch with our concerns, feelings, vulnerabilities, etc., and transform these into positive resources for our work | <i>It would appear that staff in their approach to care have to find a balance between maintaining professional detachment and becoming emotionally overwhelmed</i> |

Attention should also be drawn to a few other distinguishing features between the two cultures. For example, in the traditional medical model, there are fairly clearly defined boundaries between staff groups and, in particular, between medical staff and patients. The new culture appears to favour an approach that recognises the status of patients as persons and the value of a partnership approach to care, that treats the patient with respect and welcomes their involvement in and contribution to their care.

Redfern and Ross (1999, p. 526) draw attention to two other distinctions between the two cultures. Firstly, - dementia and, indeed, geriatric medicine - has tended to be seen as the 'backwater' of medical practice. Historically, dementia work was seen as more suited to unqualified staff with low ability and limited ambition. This however does appear to be changing, evidenced by considerable development and changes in the structure and delivery of health and social services as well as the development of aged care as a specialty in recent years and significant commitment to research into aged care health problems. The new culture on the other hand, conveys a sense of challenge; encouraging creativity and commitment in dementia care work. Secondly, the new culture operates on the belief that staff must be appropriately skilled, given support, and have their own personhood respected and valued, if they are to give person-centred care to patients. In the old culture, meeting the personal and psychological needs of staff is not a priority - being professional entails keeping your personal feelings to yourself and your private life separate from your work life.

It does appear that the new culture, which has its roots in the Kitwood person-centred approach to care, has arisen as a reaction to the traditional medical model (Redfern & Ross 1999, p. 527). Kitwood's (1997, p. 135) outline of the two cultures and his portrayal of the old culture based on the medical model does seem to be somewhat exaggerated with a tendency to caricature, even though he insists 'it is not a parody'. However, he does seem to idealise the new at the expense of the old, in his effort to draw clear distinctions between the two approaches.

Central to both models is the issue of how 'personhood' is understood - the prevailing view underpinning the medical model being that dementia destroys whatever it is that makes us a 'person'. This position, as outlined above, has been challenged by the psychosocial

approach, based on an increasing body of research that suggests the claim that the 'person' is being destroyed may be premature and this should rather be recognised as a complex and highly emotive area of professional debate. The temptation to over-simplify the approaches or polarise the views must be avoided. However, the crux of the matter appears to be whether we go along with the view that the impact of the disease is such that what we call 'the person' gradually disintegrates or we hold to the belief that there are still ways of rediscovering and sustaining personal identity (Goldsmith 1998, p. 26). These are somewhat exaggerated alternative positions, yet they do reflect the divide between the two approaches. It is easy to suggest that the medical model dehumanises people with dementia by treating them as non-persons, but it must also be asked if the Kitwood personhood approach does not tend to sentimentalise a terrible disease. Does the Kitwood approach recognise the illness for what it is - something that damages the brain, that is progressive and relentless in nature, and against which it is difficult to sustain hope? Chapter 3 will examine these and related issues through an exposé of practical approaches to care.

2.8 Re-Thinking Personhood and Person-Centred Care

While Kitwood's person-centred approach to care has been critiqued for its lack of empirical evidence in support of this approach, (Adams 1996; Harding & Palfrey 1997) more recently attention has been directed to the apparent failure of person-centred care to 'fully capture the interdependencies and reciprocities that underpin caring relationships' (Nolan et al 2002, p.203)

Nolan et al (2002, p. 204) further suggests that there is an absence of the "mutual appreciation of each others knowledge, recognition of its equal worth, and its sharing in a symbolic way to enhance and facilitate joint understanding" in Kitwoods person centred approach to care. These points of departure from the Kitwood approach underpin and define a theory for relationship-centred care. "This approach draws on triadic approaches towards dementia care together with conversation analytic work to develop the conceptual and theoretical basis of care exchanges with dementia care triads". (Adams & Gardiner 2005, p. 195)

Triads comprise the person living with dementia, a carer and the health and social professional. (Adams & Gardiner 2005, p.185). In his critique of Kitwood's work Adams and Gardiner (2005) pursue their establishment of a theory for relationship-centred care by establishing that:

“the experience and behaviour of people with dementia and their carers are continually being socially constructed through the interplay conversational and social practices undertaken by dementia care triad members”. (Adams & Gardiner 2005, p. 195)

A relational approach to providing care for people living with dementia continues to focus the attention of carers and professional practitioners. In a paper examining the care provision for people with dementia. Greenwood, Loewenthal and Rose (2001) explore the potential benefits associated with an approach to care that emphasises the importance of relationships. This paper is based on a case, which illustrates an approach to caring influenced by the Continental philosopher, Emmanuel Levinas. The approach gives primacy to the relationships that make up caring and not to a method that set out to achieve an identifiable objective. The emphasis is on a mutual responsibility within the provision of care. The hypothesis of this study was that a person has a greater opportunity to develop their potential by establishing the importance of relationships in providing care by means of education and training of the people involved. “The beneficiaries might be the caregiver or the person in receipt of care’. (Greenwood, Loewenthal & Rose 2001, p. 583)

In another study based on 74 interviews with 20 spousal couples consideration is given to the relevance of ‘awareness context theory’ to an understanding of the everyday lives and especially the relationship of partners living with dementia (Hellstrom, Nolan & Lindh 2005, p. 270). In agreement with several other authors, the relational elements of dementia exert a considerable influence according to the Hellstrom et al study. This body of work argues that rather than concurring with Kitwood’s assertion that the person comes first, the research suggests that ‘for spouses at least, the relationship is often equally important’ (Hellstrom et al 2005, p. 286).

The Hellstrom et al study (2005) takes a constructivist grounded theory approach to the exploration of the impact of dementia on the daily living and relationships of older spousal couples. They draw on ‘awareness context theory’ (Glaser & Strauss 1965) and the ‘dynamic of dementia’ (Keady 1999) to develop greater understanding using Glaser’s (1978) process of ‘emergent fit’ to provide further insight into how couples work to construct awareness in a way that helps maintain a sense of ‘self’ for the person with dementia and the integrity of the relationship between couples. “It is suggested that a ‘mutual acknowledgement’ of the diagnosis and a subsequent focus on maintaining a meaningful life in the present combine to create a ‘nurturative relational context’ in which living with dementia unfolds” (Hellstrom et al 2005, p. 270).

In a critique of Kitwood’s vision within the context of a discussion on dementia from the perspectives of sociology and philosophy, Davis (2004) cautions against an over

investment in the endurance of personhood, which he attributes to Kitwood. Far from being overly critical of Kitwood, Davis begins by presenting a challenge to the biomedical view of dementia as a disease and in doing so explores Kitwood's contribution in support of the need for alternative perspectives and practices.

However, Davis is concerned about what seems to be Kitwood's resistance to the notion of a loss of personhood, from the point of view of its implication for primary carers. According to Davis:

'...he (Kitwood) must allow for a loss of personhood, for to deny this is to denounce the legitimacy of primary carers who no longer recognize a spark of their former relationship....in postulating that personhood can ultimately be sustained, he (Kitwood) prevents the initiation of a grieving process that should begin with the involution of the sufferer" (Davis 2004, p. 377). Davis not only denounces the 'seductive nature' of Kitwood's arguments, advising that they should be resisted for the purpose of facilitating ongoing debate "as to the status of people with dementia and how they are positioned with respect to their loved ones" (Davis 2004, p. 377).

Davis is ultimately concerned with the question of what constitutes personhood and what actually remains of it following the onset of dementia. He concludes his critique of the sociological and philosophical construction of dementia by suggesting that it might offer a way of approaching what he considers to be a very real dismantling of the self.

There currently exists an emerging body of research based on ethnographic and narrative approaches which have the potential to greatly illuminate our understanding of dementia through reflections on selfhood, as a basis for rethinking person-centred care. For example a study by Basting (2003) which examines the narrative construction of Alzheimer's disease in three autobiographies claims a clear sense of 'self' is reflected which contrasts strongly with the idea that Alzheimer's disease entails a loss of 'self' as suggested for example by Davis above.

In her analysis of the three narratives Basting draws on Hava Golander and Aviad Raz's (1996) work on identity (Golander & Raz 1996) which offers a useful distinction between 'personal' identity – or one's awareness of one's self, from 'social' identity referring to the way we are perceived and interact with those around us. Basting elaborates:

'I see personal and social identity as two ends of a continuum. Both are cultural constructs ... If personal identity is a site of self-reflection in which agency is enacted, social identity tends to be a site where we are acted upon by others. The 'whole' self is created by and experienced on both ends of the continuum simultaneously'. (Basting 2003, p. 95)

A key point of Basting's conclusion – based on the three narratives – is the evidence illustrating the fact that there are more ways to express the self than simply by

retaining/displaying control over one's memory. This insight was drawn from narrators' abilities to empathise with others, contemplate their fact and express feelings, which Basting sees as alternative ways of expressing selfhood, thereby helping to 'dislodge us from this rock of individuality upon which we have run aground' with respect to memory retention. According to Basting memory can be used to affirm and define the self, but always in relation to others. 'This is the hubris that Alzheimer's narratives expose: we cling to the mistaken notion that personal memory alone constitutes selfhood' (Basting 2003, p. 95).

Basting's conclusions are recognised and advanced by Kontos's (2004) discussion on ethnographic reflections on selfhood using a framework of embodiment that integrates the perspective of Merleau-Ponty (1962) and Bourdieu (1984) in particular. Like Basting, Kontos argues, the insistence that selfhood can be exclusively defined in terms of cognition is merely a reflection of how symbiotic memory has become in Western thought, which separates mind from body, which has traditionally viewed the former as superior to the latter. Using a framework of embodiment the Kontos paper presents the findings of an ethnographic study of selfhood in Alzheimer's disease in a Canadian long-term care facility. The findings of the study argue and demonstrate that selfhood persists even with severe dementia, because it is an embodied dimension of human existence. Kontos argues:

'...that selfhood is characterized by an observable coherence and capacity for improvisation and sustained at a pre-reflection level by the primordial and socio-cultural significance of the body'. (Kontos 2004, p. 829)

Kontos also believes that selfhood can remain intact despite the debilitating impact of the progression of Alzheimer's because the self resides 'below the threshold of cognition' and is in the pre-reflection level of experience. Kontos is eager to shift the widespread assumption of the interdependent nature of selfhood and cognition to a greater recognition of the way in which humans are embodied (Kontos 2004, p. 846).

This theme is developed further by Kontos in a later study, which directs attention to embodied selfhood in Alzheimer's disease, for the purpose of rethinking and enhancing person-centred dementia care. According to Kontos to ignore the importance of the pre-reflective level of our existence is to fail to understand and take into account a fundamental dimension of how even people with severe dementia are capable of engaging with the world. Kontos elaborates:

'Conceptualizing selfhood as essentially 'the human being in relations to others' (Kitwood & Bredin 1992, p. 275) is to miss something vital about personhood namely the existential expressiveness of the body in its relations to the world, and our socio-cultural ways of being-in-the-world. It is to miss how the pre-reflective body defines the individual as a person and gives substance to the human self'. (Kontos 2005, p. 567)

What Kontos's body of work suggest is that the body's potential for innovation and creative action needs to be explored for the purpose of finding alternative ways of understanding personhood and rethinking person-centred care. It is not suggesting that the concept of personhood or embodied selfhood encapsulates all aspects of the body-self. Rather, it encourages the promotion of a perspective on the body and selfhood that provides new insight and direction for investigation of Alzheimer's disease based on the belief that despite the ravages influenced by neuropathology, the Alzheimer's discourse can be enriched by an ongoing commitment to and illumination of our understanding of these concepts.

2.9 Conclusion

The Kitwood model, with its psychosocial orientation to the care of dementing patients, appears to 'humanise' the overall approach to care, and must be acknowledged to provide an appealing contrast to the traditional medical model, which has been criticised for its impersonal and paternalistic approach to care. As Adams (1996, p. 953) notes, Kitwood's emphasis on the preservation of personhood, is likely to appeal to nurses because of their belief in a *person-centred* rather than a *task-oriented* approach to the nursing care of dementia patients. However, according to Adams, Kitwood's approach is inadequate because it is not supported by empirical evidence and he fears it may be lost in the same way as many other innovative, person-centred approaches to nursing have been over the years. There is little indication that Adams' fears are about to be realised in fact, as indicated earlier, for developments in individualised care and improvements in patient care environments, are indebted to Kitwood's work and appear to be gathering momentum.

The advent of 'personalised' approaches to care and the new culture of dementia in particular, does appear to have arisen as a reaction to the traditional medical model. While the latter has been severely criticised, because it has some obvious limitations, are we to assume therefore, that it has no place in the treatment and care of dementing patients? Is there no 'middle ground' between these two polarised approaches to care? This is a matter to which we must turn our attention.

Despite the obvious differences between the medical and psychosocial approaches to dementia care, there is agreement among theorists that the models are not mutually exclusive and are best seen as complementary and interdependent (Parker & Penhale 1998, p. 25). In other words, an attempt should be made to recognise the fact that a therapeutic approach, such as massage, may be sufficient to calm a disturbed patient on an occasion, while the

administration of medication may be the only feasible way of preventing a severe dementia sufferer from harming self and others in another situation. According to Redfern and Ross (1999, p. 527) the medical approach is not incompatible with Kitwood's portrayal of the new culture, but it is crucial that the former is seen to provide a partial rather than a full description of dementia, as was previously the case. As indicated in the discussion in this Chapter, there are other voices to be considered whose contribution challenges and expands on the medical model and Kitwood's person-centred concepts. These contributions encourage the promotion of a perspective on the body and selfhood that provides new insight and direction for further investigations of Alzheimer's disease. In effect, this means the search should continue in the future to find means and methods of retarding or curing the progress of dementia, while at the same time giving consideration to how sufferers' and carers' experience can be used to help interpret and manage the disease.

CHAPTER 3:

Understanding Nursing Care Practice

3.1 Introduction

In the previous chapter it has been argued that some progress is being made in the development of new and more informed understandings of dementia in the care of the elderly. Against this background the overall aim of this chapter is to discuss a number of key elements that are required to ensure the delivery of high quality care and improved quality life for patients in advanced stage dementia. Namely:

- Implementation of a good organisational philosophy of care aimed at optimising the quality of life and reducing the physical, psychological and spiritual suffering of people with dementia
- Appointment of well-trained carers and provision for their on-going professional development in appropriate knowledge and skills
- Effective care planning, based on sound assessment, implementation and monitoring of care plans, evaluation of these against clear objectives and feedback to the organisation for the purpose of continuous service improvement
- Provision of well-designed physical care environments which can optimise the scope for patients to maintain their social skills, maintain their mobility, continence and autonomy, even in the advanced stages of dementia.

The Chapter begins by focusing on individualised patient assessment, for the purpose of identifying the specific needs of patients in the advanced stages of dementia, and distinguishing these from those in the earlier stages. Our first object is to avoid confusing the needs of patients in the mild or moderate stages of dementia with those who are living in the advanced or terminal stages and, secondly, to avoid perpetuating the trend of putting people with advanced dementia into the 'too hard basket' — because of the limited skills of many practitioners to understand or interpret what the dementia sufferer is struggling to express.

I will first explore what constitutes 'quality of life' in advanced dementia, taking account of:

- the medical issues to be addressed,
- the psychiatric symptoms to be managed and,
- the engagement of patients in meaningful activities. (Volicer & Bloom-Charette 1998, p. 8)

An underlying concern in this chapter is the fact that while some carers, such as nurses, are professionally trained, by far the majority of those people involved in dementia care delivery are not formally trained. All staff are generally required to receive in-house or on-the-job training and this seems to be provided in all care settings we have observed. However, its quality and effectiveness can vary considerably for a wide variety of reasons. A related concern is: - what is involved for the carer in making the transition from new recruit to skilled practitioner? To answer this question it is necessary to clarify what assumptions are made about 'nursing care' and the routine and culture of ward life, and how the new carer begins to learn what these mean in practice through the process of socialisation and induction. What is entailed in being a carer and how carers actually manage in given situations will be explored through consideration of a number of scenarios which illustrate the challenges carers experience in a ward environment. An attempt will be made to answer a number of specific questions, namely:

- What understandings, perceptions and methods are used to determine an appropriate course of nursing action in a particular situation?
- What kinds of factors force carers to prioritise nursing tasks and activities, and what rationalisations underpin such decisions?
- How do staff members ensure the delivery of high quality patient care and sustain their ability to conduct nursing practice in an ethical way?
- Who determines what are ethically right and wrong decisions and actions in relation to care of patients and the treatment of dementia?
- How do carers feel about, and resolve, situations for which there are no apparent right or wrong answers? [Moral dilemmas can arise in situations of ambiguity and uncertainty, and traditional principles and ethical codes may be of little help in resolving them.] (Caper 1997, pp. 288-289)

This chapter will conclude with an overview of care settings in terms of patient mix, patient numbers and in particular on how different features of such environments may impact on staff, patients and the process of care delivery. The reason for giving attention to the environment of care is the growing evidence to suggest that building design and living arrangements can have a major impact on patients' behaviour (Alexander 1997), and that contextual influences must be taken into account as an aspect of care delivery (Stokes 1990, p. 73).

Finally, I will seek to clarify the strategies carers use to deal with the stress of working with demented patients to survive personally and professionally and how they negotiate work relations with colleagues and patients. This analysis should help to throw light on how

difficult it is to bridge the gap between ideal standards of nursing care for elderly people with dementia and the day to day reality of care, particularly for patients in the advanced stages of dementia.

3.2 Quality of Life in Advanced Dementia

In the decades since the inception of the NHS, there have been many significant changes in health care due to the impact of various political, economic, social, scientific and technological developments (Jolley & Allan 1989, p. viii). During this period, nursing has been influenced by, and responded to, these different prevailing influences, and continues to do so (Jolley & Allan 1989, p. viii).

Dealing with the health care needs of older people, including those living with dementia, is gaining greater prominence as an area requiring specialised knowledge, research and training. Recent developments in gerontological nursing reflect a greater understanding of a number of facts, including the diversity of older people in terms of groupings and needs, resulting in the placing of greater emphasis on the importance of individual biography and the impact of psychological influences on the health of elderly people (Heath & Schofield 1999; Pickering & Thompson 1998; Norman & Redfern 1997).

Many recent studies, which stress the need to look at the powerful influence of personal history, a patient's current circumstances and the impact of factors such as diet and environment, base their findings on literature emerging from several sources including: ethnographic studies, psychological testing, personality inventories, cross-cultural surveys and longitudinal studies (Norman & Redfern 1997, p. 38). As discussed in the previous chapter, this particular emphasis on care has been well developed in recent years in relation to the treatment and understanding of people with dementia. For example, Holden and Woods' recent work on *Positive Approaches to Dementia Care*, outlines practical ways to provide direct care and to facilitate good communication, stressing the need for a positive attitude to the dementia person's quality of life (Holden & Woods 1995).

While 'quality of life' has an apparently obvious or commonsense meaning (Pickering & Thompson 1998, p. 286), it has proved a notoriously difficult concept to define. A scan of the research on this topic suggests that earlier works on quality of life sought to impose values on what was considered to be important to a definition of life as being 'good'. More recent research, however, reflects the attempt to conceptualise 'quality of life' as a relative concept that encompasses the 'user's views' as well as those of carers and significant others

(Adams & Clarke 1999, pp. 157-158). While no single agreed definition yet exists, there is a degree of consensus that 'quality of life is the multi-dimensional evaluation by both intra personal and social normative criteria of the person's environment system' (Lawton 1991, pp. 3-27). For example, one of the more recently developed quality of life models identified five components of the construct, each of which can be measured objectively and subjectively. These components of the multi-variate constructs are: physical, social, emotional and material well-being, as well as development and activity (Felce & Perry 1995). Numerous other studies have identified similar variables in attempting to define quality of life (Vetter, Jones & Victor 1988; Kayser-Jones 1981). According to Ladislav Volicer and Lisa Bloom-Charette (1999, p. 6):

The most difficult population in which to delineate quality of life issues is individuals with advanced dementia, because cognitive changes affect one's subjective experience and subjective verbalisation of quality-of-life issues.

Miesen and Jones (1997, p. 331) elaborate further by drawing attention to the fact that it must be accepted that a time may come when a person may no longer be capable of expressing their will or of being understood, however desirable it may be to include users' views in defining quality of life. Having earlier established autonomy and competency as leading ethical principles within the context of defining quality of life, Miesen and Jones recognised the fact that for a person in the advanced stages of dementia, the principle of autonomy can no longer be considered a guideline. They do, however, also make the point that the 'concept of competency, or rather incompetency, though it may justify care-givers acting without a person's consent, does not essentially offer a solution to ethical dilemmas (Miesen & Jones 1997, p. 331).

3.3 Quality of Life Components

While there might be ethical concerns raised about the 'lack of inclusion' of the voice of the user in a definition of quality of life, more seriously, Volicer and Bloom-Charette (1999, p. 8) concluded, on the basis of an extensive review of existing measurement instruments, that no multi-dimensional quality of life instruments existed for people in the advanced stages of dementia. They have since developed a model for quality of life in advanced dementia, which includes: meaningful activities, medical issues and psychiatric symptoms. The authors consider all three factors need to be taken into account if services are to be provided that will achieve optimal quality of life for individuals in the advanced stages of dementia (Volicer & Bloom-Charette 1999, p.8).

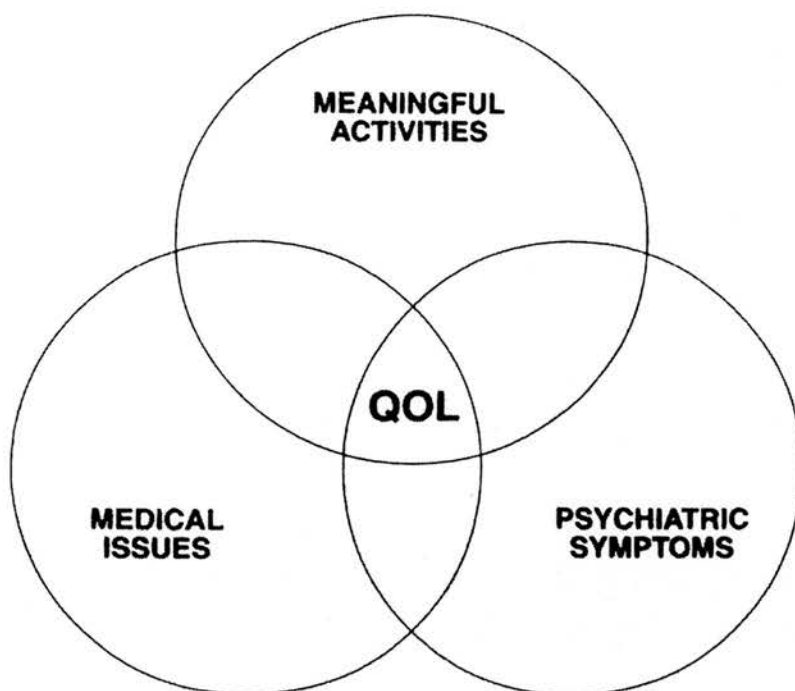


Diagram adapted from Figure 1.1 Factors involved in quality of life (QOL) in dementia.
(Volicer & Bloom-Charette 1999, p. 8)

According to Volicer and Bloom-Charette the provision of meaningful activities is the most important factor but the most difficult to achieve because of the inability of patients to initiate such activity on their own. The provision and maintenance of meaningful activity requires constant carer involvement, which the authors recognise as a challenge where resources are limited, such as shortage of staff. 'Meaningful activity' must at all times be tailored to the strengths of the individual and be cognisant of the life history of the person as well as their likes and dislikes. Providing meaningful activities for dementia sufferers requires that carers have the capacity, skills and understanding to select appropriate activities for an individual patient, and to take account of their medical and emotional states at any given time. Volicer and Bloom-Charette emphasise the importance of focusing on the remaining strengths of the patient and not on their deficits. The writers do not favour short periods of special programs: rather, maintenance of meaningful activity such as housekeeping tasks and daily-living chores e.g. folding laundry and washing dishes - activities familiar to the person.

In a presentation of this model in Perth, Western Australia in November 2004, Volicer elaborated on the importance of carers understanding the fact that the engagement of patients in tasks of a repetitive nature should not be viewed as boring, meaningless or demeaning to patients. Rather, such activities ought be perceived as a positive engagement of a patient in a task that is familiar yet new each day, because of the patient's significant short and long term

memory loss. This example alone provides some insight into the need for carers to understand dementia, its impact on patients and the importance of developing the skills necessary to engage in a meaningful and competent way with patients

In the Volicer and Bloom-Charette model, planned engagement in meaningful activity must take into account the two other quality-of-life areas identified, namely, medical issues and psychiatric symptoms. As indicated above, the authors consider participation in meaningful activity as the most important factor in the quality of life because through them patients can engage with their physical and social environment. Engagement in activities can also help reduce states of anxiety, apathy and frustration, which are indicators of poor quality life. In this way meaningful activity can impact positively on psychiatric symptoms by reducing the debilitating effects of negative mood states on quality of life. In the same way, meaningful activities can impact on medical issues limiting the effect of dementia-induced impairment of mobility. As patients progress into the advanced stages of dementia their ability to maintain mobility may become significantly restricted. Loss of ability to recognise obstacles and, therefore, the risk of falls, may result in a sedentary life which, in turn, would make patients prone to infections, deep vein thrombosis and pressure ulcers (Volicer, Brandeis & Hurley 1998, pp. 29-47). It is therefore most important that carers understand how important it is that patients should be encouraged to maintain mobility for as long as possible, for both psychological and physical reasons.

In the Volicer and Bloom-Charette model the second domain - medical issues determining quality of life - includes factors such as management of eating difficulties, intercurrent infections, chronic medical conditions and physical comfort. In summarising their exploration of each of the identified elements, it is evident that the authors are primarily concerned with the prevention of suffering and the enhancement of patient comfort.

3.4 Adopting a Palliative Approach

The same authors exhort carers to weigh the benefits of an intervention against the potential burden the intervention may pose for the patient and, in certain circumstances, the benefits may be difficult to achieve. For example, an inexperienced carer responsible for medicating a patient in the advanced stages of dementia who is incapable of making their level of discomfort or pain known to the carer, may have difficulty deciding on appropriate dosages. The authors also remind carers:

Because advanced dementia is a terminal disease for which no curative therapy exists, comfort of the patient instead of maximum survival may be the

appropriate goal of care. Aggressive interventions that produce discomfort and require patient restraints should be avoided as much as possible. (Volicer & Bloom-Charette 1999, p. 16)

These comments also apply to the management of elements comprising the third domain of the model - psychiatric symptoms. The authors advise that carers need, for example, to be very sensitive to the side effects of drugs administered to patients that may lead to other debilitating behaviours and ultimately to diminished quality of life. The emphasis here is on the need for carers to make informed choices based on attentiveness to patients' behavioural responses and the ability to recognise that, as the disease progresses, the comfort of the patient may be the most critical factor to take into account.

A summary of the critical elements of this model suggests that quality of life issues are important for all patients but in particular for those who have the least control over their environment, that is, patients in the advanced stages of dementia. The model reminds us and carers that conventional medicine still may be the most effective form of care at any given point in time. However, this perspective is to be balanced by recognition that there is considerable evidence to support the view that new and alternative approaches to care can significantly enhance the quality of life of patients in the advanced and terminal stages of dementia.

Ladislav Volicer and Ann Hurley (1998) developed this theme more fully in another text which focused exclusively on hospice care for patients in the advanced and terminal stages of dementia. In this text the authors advocate a humane approach to the care of demented persons, based on using expert medical care when necessary and appropriate, while remaining mindful of the need for person-centred palliative care in the later stages of the disease. Traditionally 'palliative care' was a term used to describe a philosophy or system of care that facilitated quality of life and death with dignity in people who were terminally ill, usually with cancer (O'Neill 2002, pp. 263-264). A similar palliative approach is becoming common practice in some care settings for patients in the terminal stages of dementia (Kaganowski 1997).

However, there is evidence to support the view that elements of palliative care need not be restricted to the final days or weeks of life. The primary goal of palliative care is to ensure the patient's comfort and, where possible, improved functioning, by addressing the patient's psychological, spiritual and social requirements (Department of Health and Ageing 2004). This approach agrees with the Volicer/Hurley and Volicer/Bloom-Charette studies, which encourage a focus on active comfort care and a positive approach to ensuring that all that can be done is done to reduce a patient's symptoms and distress and ultimately their

suffering. It is appropriate then to take a closer look at what we mean by nursing care and the practical implications for the novice carer.

3.5 Understanding Nursing Care

Peta Bowden, in a book titled *Caring — Gender-Sensitive Ethics* (1997), depicts caring as an intricate skill and intelligent practice that many feminists, in particular, have asserted it to be. She disputes accounts of the ethics of care that focus on basic principles of caring and favours an analysis of caring based in practice - working through examples and experiences drawn from practice, to reach understanding. Following this approach, Bowden moves through an impressive range of literature and explores four main caring practices: mothering, friendship, nursing and citizenship - making connections across caring practices and the ethical issues they involve. In addressing nursing care - having initially explored mothering and friendship - she focuses on the structure of professional nursing relations, which:

are formed between people whose connection with each other is primarily governed by the responsibility of one person to respond to and to service the needs of the other. Most frequently the parties are strangers to each other, not personally involved in each other's lives through ties of blood or friendship. As a consequence, the caring practices of nursing are subject directly to the determinations of publicly administered norms and structured by the demands of publicly sanctioned conduct. (Bowden 1997, p. 101)

Bowden is distinguishing here between paid and unpaid carers or lay and professional carers. From a practical point of view, it is not necessarily obvious how the care given by a lay person differs from that provided by a nurse (Thompson, Melia & Boyd 1996, p. 13), since they both provide nursing care. However, the two types of carers do actually differ in several ways as Bowden indicates. Firstly, the patient and nurse do not usually share blood or friendship ties. Secondly, in the absence of such ties, it is most probable that the nurse and patient in a professional setting, such as a hospital ward, will 'come from different backgrounds and thus not share the same outlook, culture, values and expectations' (Thompson, Melia & Boyd 1996, p. 13). Finally, and perhaps most importantly, nurses are paid carers who acquire professional qualifications and provide care on a contractual basis and 'not on the basis solely of duty, altruism or necessity' (Bowden 1997, p. 102). However obvious these distinctions might appear to be, when they get confused, as they sometimes do, in terms of how patients or their relatives define care, the outcome can be problematic - a point to be re-visited later in this discussion.

Focusing on these 'recognisable' or identified distinctions, professional nursing relations or paid carers' work, relates the discussion on the ethical import of caring practices to 'that immensely important ethico-social construct: the public/private division or domains of practice (Bowden 1997, p. 102). Recognising the fact that the distinction between public and private domains is often disputed, Bowden advises against being too cavalier in dismissing the overlap, as evidenced in the case of lay nursing for example. For Bowden the relationship between the personal and the public domains is 'complexly inter-layered' and from which a multiplicity of possible meaning can emerge.

In her commitment to the belief that caring is best analysed and understood through a process of analysing practical examples, Bowden draws much of her inspiration from the work of nursing theorist Patricia Benner (1984, p. xix), who has written extensively on the nature of clinical nursing practices and the distinctive ethical possibilities inherent in such activities. Benner is concerned with calling attention to the limits of formal rules and encouraging the practice of discretionary judgement in actual clinical situations. In doing so, she is not advocating a chaotic or anarchical approach, but rather a skilled advanced understanding of the situation, thus facilitating an orderly approach without rigid adherence to rules (Benner 1984, p. xx). Bowden interprets this as Benner recognising the importance of skilled nursing and its dependence on formal education with respect to knowledge about all aspects of patient care. However, excellence in caring emerges through 'more intuitive understanding that responds to the demands of a given situation, rather than rigid principles and rules (Bowden 1997, p. 106).

The discussion so far tends to indicate that a process of transition must take place for the person who chooses to become a paid carer - the transition from lay to professional and/or from novice to expert (Benner 1984). As the following scenario suggests this process can be challenging and fraught with difficulties for the new recruit.

3.6 Case History: The Reaction of Instinct and Experience

A learner is being shown round her new ward by the staff nurse. It is a geriatric ward and clearly a busy one. She has been told that after a quick tour she is to work with a third-year student and that by such an arrangement they should 'get straight by lunchtime.' Halfway down the ward there is a lady in her eighties, sitting by her bed. As they approach, she asks the learner to tell her the time and what is for lunch, and while speaking she secures a firm grip on the learner's uniform skirt. The staff nurse announces loudly that Mrs B is always asking the same questions because she is demented and has a grossly impaired memory. She gives no indication as to how the newcomer is to extricate herself from the

situation while conveying clearly the message that she is to be followed down to the dayroom to complete the tour of the ward. (Thompson, Melia & Boyd 1996, p. 13)

In this scenario, the learner could be a student nurse still in her teens, a trained nurse with no experience in geriatric care or a mature man or woman starting a new job as a nurse assistant with no previous experience of working in health care. While it can be assumed that a trained nurse learner will have other experience to draw on she may still be quite unsure of herself when confronted with a person suffering from dementia. Nevertheless, the focus here is on how the inexperienced learner perceives this situation and the issues inherent in negotiating an appropriate response. According to Thompson et al, this experience is likely to cause particular difficulties for the learner, based on personal values arising from family background, as well as cultural heritage and other experiences. How the learner perceives aged persons and understands or defines nursing care, for example, will be primarily based on personal values.

For the lay carer, responsible for another person - through the bonds of family or friendship - the needs of the person in question rather than the demands of a large organisation are the pivot of decision-making, but 'in professional nursing, by contrast, there exist not only institutional pressures but also the need for congruence between the values of an individual and of the profession' (Thompson, Melia & Boyd 1996, p. 13). Clearly the potential for conflict at this point in the learner's career is great indeed - finding herself perhaps for the first time unsure of the values that stood her in good stead in all other situations. She will also be anxious to learn as much as possible as quickly as possible, being in constant fear of causing a disaster by doing something wrong.

3.6.1 Shared Meanings

The new recruit is for a period of time likely to feel dislocated from what is familiar and bewildered by many of the activities on his or her first ward. They would be just beginning to learn the meaning of the implicit and explicit rules or conventions which sustain institutional and staff expectations of ward routine.

The actions of others around them do not make sense and consequently they do not know what should be done next...they do not know the pattern of conventions, which make sense of the actions they observe. (Abraham & Shanley 1992, p. 9-10)

In reality, the learner is likely to feel anxious and unsure, conscious of the need to build up an understanding of the situation and a repertoire of skills suited to the demands of the new environment. This person will then be anxious to enter into the

world of shared meanings around them (Abraham & Shanley 1992, p. 10). 'Meanings are learned by individuals in social interaction, behaviour is constructed and circular (Meltzer, Petras & Reynolds 1975, p. 3).' Symbolic interactionism (primarily influenced by the work of G.H.Mead) argues that the individual has no reality outside of the social group which, in part, determines him and which he, in turn, determines (Meltzer, Petras & Reynolds 1975, pp. 1-3). It regards society and the individual as inseparable and interdependent. The self originates in social relationships or, more simply, human beings construct their realities in a process of interaction with other human beings (Harding & Palfrey 1997, p. 12).

The new recruit, through interaction with other workers, will be introduced to a set of shared meanings which are often taken for granted but which will enable the learner to move from a state of bewilderment to making independent judgements and eventually become able to introduce other newcomers to ward schedules, routines and culture. In other words, the subjective reality of the ward is established and maintained through a process of socialisation or induction, through which the new recruit learns by observing routines and inter-subjective relationships so that they become subjectively meaningful to self (Harding & Palfrey 1997, p. 15). In the same way that symbolic interactionism holds that self-formation is the result of dynamic inter-relationships between the individual and his/her social context, it is claimed that 'professional identity emerges through a process of self-formation in which social interaction and self-reflection are the basic process. The internalisation of values is an integral part of this process...' (Fagermoen 1997, p. 4). As learners progress through socialisation into their new role/s, they become members of the ward culture in the sense that they become part of the shared set of meanings and understandings which constitute that culture (Abraham & Shanley 1992, p. 10).

As Thompson et al (1996) note, the new recruit is likely to make the transition at a functional level quite quickly, but may take much longer to make the deeper adjustments, regarding her personal fears and feelings and negotiating the integration of the values and attitudes of professional nursing (Abraham & Shanley 1992, p. 10). In other words, she has to work out how she can respond with respect to the old lady tugging at her skirt while meeting the expectations of the staff nurse who appears to dismiss the patient as a nuisance to be ignored. Essentially the new recruit must learn to manage and balance competing demands and, through this process of socialisation, the example of colleagues and their personal qualities, develop the ability to

understand and prioritise the critical elements of nursing care and what it means to be a professional carer.

3.6.2 Sources of Carer Stress

There is evidence from various studies that significant pressures exist in nursing which have adverse consequences for carers and ultimately for patient care. In a 1989 study on occupational stress in nursing (McGroth, Reid & Boore 1989), it was found that 67% of respondents said that having insufficient time to perform duties in a satisfactory way was a key source of stress. A further 54% considered the experience of rationing scarce resources to be stressful. There now appears to be substantial agreement from the findings of many similar studies that experience of understaffing is commonly identified as the most stressful aspect of nursing work — more than dealing with dying patients or distraught relatives, for example (Abraham & Shanley 1992, p. 229).

In another 1989 study in the United States, which surveyed 1801 general nurses on their experiences of tension, tiredness and methods of dealing with these experiences, numerous sources of stress were identified. The sources of work stress were identified and listed in order of importance: work overload, difficulties in relationships with other staff, difficulties involved in nursing critically ill patients, concerns over patient treatment and nursing patients who fail to improve, such as older people (Abraham & Shanley 1992, p. 229). In this study a number of issues were identified under each source of stress listed. For example, work overload referred specifically to being accountable for the nursing care of too many patients, coupled with experiencing difficulties in maintaining high standards and being unable to support colleagues adequately due to staff shortages. This all conveys for nurses a sense of not being in control of their workloads, of their work environment or the caring process (Street 1995, p. 41).

Older people are statistically the largest single group within most modern health services and are cared for by nurses in a variety of health settings. Nurses are therefore in a pivotal position to influence the quality of care and ultimately the quality of peoples' lives (Marr & Kershaw 1998, p. 111). However, many studies have shown that communication with older patients and relationships between nurses and older people - especially those living with dementia - can be problematic, affecting the nursing care process (Marr & Kershaw 1998, p. 111). It would also appear - given the specific issues identified in the Kenny and Campbell reports relating to the stress

factors identified by carers - that the influences above give rise to competing and conflicting demands. These have to be managed in the interests of delivering an acceptable standard of patient care. It is against this backdrop that we must turn attention to the nursing care of elderly people with dementia.

3.7 The Practice of Caring

Pickering and Thompson (1998, p. 196) say: 'The beliefs and values held about nursing and people will affect how care needs are identified, prioritised and managed'. In the same vein, Bishop and Scudder, discussing the relationship of practice and caring, express the view that nursing 'care and practice are integrally related in the relationship of nurse and patient. Thus, nurses who practise well, experience being a good nurse and a caring person as one. In caring practice, good practice requires excellent, rather than 'extra' care' (1991, p. 105). They elaborate further on the link between caring practice and good practice, and set out to establish that good nursing requires caring for the well being of others out of an understanding of the meaning of good practice, informed by a concern for all aspects of the person. They consider these considerations to be the key requirements of ethical caring.

Verena Tschudin, in making the connection between ethics and caring, sees the latter as the basic act of nursing. Expanding on this link, she claims that ethics is caring, to act ethically is to care, 'caring ...may be seen to be higher than laws, or more far reaching than ethical theories, but fundamentally it is basic to ethics' (Tschudin 1986, p. 15) Focussing more specifically on ethical practice, Purtilo and Cassel draw attention to technical and ethical competence. Making the point that it is unethical to practise a profession if one is incompetent to do so, they add:

Ethical competence thus includes technical competence but reaches far beyond it to a sense of honesty in dealing with colleagues and clients, a sense of the goals of one's work, and a sense of duty to uphold the standards of the profession as well as a duty to act on behalf of the client or patient. (Purtilo & Cassel 1981, p. 20)

Purtilo and Cassel explain ethical competence with this example. 'A medical records administrator is technically competent to record and classify information from the chart of a patient', but needs ethical competence to make decisions about disclosure of that information' (Purtilo & Cassel 1981, p. 20). In the same way a nurse may be competent to give an injection or administer medication, but will need ethical competence to know how to deal with the patient's offensive or aggressive behaviour.

Returning to the ethical dimensions of the nurse-patient relationship, we are reminded that care and ethical practice are highly contextual or, to quote Benner, 'caring (and by implication ethics) is local, specific and individual ... one thing is clear: almost no intervention will work if the nurse-patient relationship is not based on mutual respect and genuine caring' (1984, p. 209). The Briggs 1972 (HMSO) Report in considering the nature of the nurse-patient relationship includes the attitudes, knowledge and skills that go towards its development. Briggs identifies nursing care as:

encompassing kindness, responsibility, skill intelligence, and sensitivity ...(and) also recognises nursing's integrative function...in terms of understanding and responding to a person's physical, social and psychological needs. (Briggs as cited by Pickering & Thompson 1998, p. 197)

In the thirty years since that report, there has been a large volume of literature on caring, which continues to shape and influence approaches to practice in all areas of nursing.

Drawing on some of the findings of recent research, which evaluated care in a new facility specifically designed for elderly people with dementia, Elizabeth Barnett comments in fairly stark terms on the heavy psychological and emotional price that is paid by staff, managers, patients and relatives involved in the process of giving and receiving care.

To spend each working day face-to-face with the emotional pain and desperation of elderly clients with dementia could be a draining experience of disempowerment and despair. To manage such services, often with little understanding of the needs of the client group, but squeezed between the diminishing resources on the one hand and the clamour of over-stressed staff on the other, could equally be a recipe for cynicism and despair. (Barnett 1997, p. 6)

While the focus here is on the nursing care of elderly people, it could apply to other areas of nursing practice as well. There are no doubt moments in every nurse's experience that can be recalled with positive feelings; for example, pride in a job well done, or positive feedback from patients and relatives on good care delivery. However, day-to-day life on a ward is made up generally of routines, schedules, demanding patients, anxious relatives, competent and incompetent colleagues and a lot more. Ultimately the outcome of high quality patient care will depend on how well a team leader and her carers can manage on a daily basis these and other challenging elements of routine care delivery.

For example inflexible, task-oriented approaches appear to predominate in many care environments and, as a result, many carers who recognise the importance of individuality and uniqueness will struggle with the realities of practice (Ray 1999), e.g. having a flexible breakfast schedule that caters for the differences in the needs of patients as people, and their preferences with regard to what and when they wish to eat. If the aim is to maximise the patient's personal control, that is, allowing them to continue being in control of as much of

their life as possible, then adopting a flexible breakfast schedule would be necessary in a ward that caters for patients with dementia. This may of course be quite difficult to manage in practice. Patients wake up at different times with little or no awareness of the needs of others or sense of urgency about routines being completed. Meeting their demands may cause breakfast-time to be spread over a few hours. It will also impact on how and when other tasks can be undertaken or completed, for example, making beds and the toileting and bathing of patients. In effect, this means that a person-centred approach to the breakfast schedule, for example, can seriously disrupt ward schedules, and, challenge staff to find creative ways of achieving the tasks and goals that define good nursing practice.

Managing a confused person who becomes incontinent and starts to urinate in the 'wrong' place can be difficult and distressing for carers (Stokes & Goudie 1999, p. 149). Many writers have observed that helping patients to bath, wash, use the toilet and eat are situations 'fraught with potential for infantilisation, abuse, sexual misunderstandings, challenging behaviour, undermining dignity, poor hygiene and so on' (Elgar & Marshall 1998). In a study on physical care and quality of life in residential homes, Hughes and Wilkin found that toileting routines in a homes where over 50% of patients were incontinent were 'regimented, dehumanising and completely without privacy'. The characteristics of the toileting process have to be seen as a consequence of the need to toilet large numbers of disabled people in a very short space of time (Hughes & Wilkin 1987). Hughes and Wilkin observed that the staff involved could not be described as brusque, cold or uncaring, rather the situation highlights the conflict that can arise in communal settings, between the need to get the task done and ensuring that the dignity of the patient is respected. But, the border-line between necessary efficiency and completion of routines and poor quality care, abuse or even unethical practice may be difficult to define in actual practice (Redfern & Ross 1999, p. 251).

Perhaps one of the most controversial issues in care management is the use of chemical, physical and other forms of restraint for the purpose of managing so called problems or challenging behaviour of patients. For many decades physical restraints were used in many countries for managing falls, resistance to medication, agitation and wandering behaviour (Evans & Strump 1989). The advent of the person-centred approach to care brought some change in attitude and practice based on the understanding that individuals both with and without dementia do not tolerate or respond positively to the use of restraint. Some of the negative consequences of restraints include withdrawal, anger, depression and humiliation, in addition to physical changes in body chemistry, resulting in respiratory problems and cardiac stress (Rader 1995, p. 254). A key issue affecting recourse to physical

or chemical restraint, is nurses' understanding and tolerance of challenging behaviour and the need for them to be able to explore alternative and more effective methods of managing difficult patients.

These are just some of the contextual issues that impact on carers in the process of meeting the needs of patients.

3.8 The Caring Professional

How well individual carers or teams manage to provide a professional service is dependent upon their level of knowledge and understanding of the task at hand and their having the necessary skills and sensitivity to meet the patients' needs in a caring way. The following scenario is an example of sensitive professional practice, which demonstrates the positive impact of combining well honed skills, good understanding of the procedure and a sensitivity to the patient's feelings.

3.8.1 Learning To Pass a Nasogastric Tube.

The story as experienced by a student nurse.

I was a student nurse and I was being taught by the enrolled nurse how to pass a nasogastric tube on a patient. The lady we were working with was quite poorly. She had lung cancer and had had fluid drained from her pleural cavity twice that week. The enrolled nurse explained to her exactly what we were going to do and how much better she would feel. The student was quite clear about how unpleasant the tube could be when it was going over the back of her throat. He then explained it again to me and she watched like a hawk, holding the tube he had given her in her hand. After all the preparation, he proceeded to put the tube up to her nose, and lifted her two hands and wrapped them round his. 'At any time when you want you can stop this,' he said. So she did, three seconds later. The second time, he was just as patient. Eventually, with tears pouring down her face, she pushed at his hand to 'help' the tube going right down her throat. After she was all tidied up and settled, and some of the bile had been drained off, we all held hands for a second, and he made her laugh by inviting her to help with the intubations of any other patient who might need it. (Davies 1995, pp. 147-148)

This story was related by a student nurse for the purpose of demonstrating the paramount importance of actively managing the feeling states of nurse and patient, as well as showing how a patient can be encouraged to take control, if the nurse remains open and willing to cope with the uncertainty that ensues (Davies 1995, p. 147-148). The scene so graphically described by the student nurse - passing a nasogastric tube in

such circumstances is clearly not a task for the squeamish nurse or patient. But, what is it about this story that might lead us to conclude that this is an example of 'good nursing care' or that the enrolled nurse is the sort of person many might want to have assist them if they ever had the need to undergo such a procedure? And, what elements were present in this scene that combined to convey a real sense of good nursing care and by implication sound ethical practice?

The evidence suggests the enrolled nurse understood the task at hand and was confident about how to proceed. This meant he was knowledgeable about the procedure, not only from a scientific perspective but also in terms of the potential discomfort for the patient and the feelings it was likely to evoke. To guard against the patient feeling overwhelmed or suffering undue fear or discomfort due to the movement of the tube, the nurse reassures the patient by encouraging her to take control of the movement. This approach reflects understanding of the patient's situation, physically and emotionally. The nurse was sensitive, but ensured that the patient remained autonomous, and so proceeded with the task in an interdependent manner. This intervention and indeed the nurse-patient relationship appeared to be based on trust, respect and genuine caring.

The enrolled nurse appeared to act in an engaged sense with the patient, finding an appropriate balance between being too distant or too involved. The procedure engaged both the nurse and patient in an interdependent process, with neither person passive nor totally in control or autonomous. The use of humour and the brief holding of hands at the end of the procedure, more typically referred to as 'an embodied use of the self' (Davies 1995, p. 150), or 'embodied knowledge' (Savage 1995, p. 67-86) are recognised as primary tools for establishing rapport and helping a patient relax. The enrolled nurse in question seems to have had the ability to utilise humour and closeness in a way that is reassuring without being condescending, and respectful without being intrusive.

3.9 The Patient's Perspective

The above example of how a procedure can be managed in an appropriate and mutually acceptable manner could be described as an example of well-orchestrated management of a delicate and potentially difficult nursing procedure, underpinned by a caring nurse-patient relationship. However, for a variety of reasons some nursing procedures

can result in conflict, confusion and varying degrees of dissatisfaction as the next scenario illustrates.

3.9.1 'Doing Things She Really Didn't Want To Do.'

Laurel Rust, a care assistant described her relationship with one of the residents in the nursing home where she works. The resident's name is Amy.

On one particular day, Amy, during an extended tirade, remarked:
And I'm tired of people who come by just to be nice and say hello,
good-bye!

Later Laurel asks Amy:

Do you think I come here just to be nice?

Amy replies by saying:

Well I think maybe you do, because I've seen you doing things you
don't really want to do.

But she concludes this statement by remarking:

But you don't know what this means to me

Later Laurel reflects:

But I drove home wondering if Amy trusted me, if I was another
intrusion, some kind of macabre voyeur. She was right: I often do
what I do not want to do. She'd blown the whistle on my little
story. But not this, not seeing her, not coming to know her. I began
to see the ways in which I needed her.

(Rust as cited by Killick & Allan 2001, p. 42)

The dialogue above suggests that Laurel's negative feelings, associated with the tasks she had to undertake, were quite transparent to Amy. The latter made it very clear that she felt angry toward staff members who pretended to be interested in her welfare. She also indicated that because interactions were superficial she felt staff didn't know the depth of her feelings, suggesting there was no real personal relating taking place. Laurel obviously felt confronted by Amy and was concerned that the level of trust in the relationship might not be what she thought it was or would wish it to be. It also raises questions about what they both understood 'caring' and 'helping' to mean. Laurel's reflection on the way home revealed her concern for the relationship, her recognition of the importance of trust and her openness to scrutinise some of her own motives for being a carer without becoming defensive or angry.

Here, the work of Benner and Bowden, on developing and sustaining relationships with people has served to emphasise these as forming a critical part of nursing care (Kitson 1987). This view is supported by the Fosbinder (1994) study on patient perceptions of nursing care, which revealed that patient's views of good care were directly linked to the quality of relationships with staff. According to Marr and Kershaw too, a nurse who is able to form good relationships with patients possesses a

number of personal qualities, including tolerance, understanding, humour, patience, self-awareness, respect, empathy and integrity. These are the same qualities that one might expect to find in a good practitioner in other fields of work where relationships are central to practice.

These human qualities are ones which most people would espouse, as they are integral to harmonious human relationships. However, the way in which they impact on or are employed in the nursing care process ought to be decidedly different to relationships bound by friendship or family ties. For example, humour - mentioned earlier - differs in its expression and character from one family to another. In nursing, humour is used to minimise potential embarrassment, and when combined with an air of detachment, a careful use of language and a 'matter-of-fact' manner, forms a core element of a professional approach and the successful social management of an otherwise unusual situation (Lawler 1991, p. 112). In this context humour is used as a way of managing and protecting the feelings of nurses and patients. Minifisms - a tendency to minimise the importance of something (Collins English Dictionary 1998, p. 991), is a nursing-specific way of using humour (Lawler 1991, p. 169), something that becomes part of the socialisation of the new recruit. It should be pointed out that a nurse's sense of humour may not be appreciated by a patient, and may even cause unintended offence, so sensitivity, especially to cultural differences, is important here as well.

In the same way the appropriate place or use of the other qualities identified above, has for some writers been a cause for concern, because of the long standing advice to carers to 'avoid getting too emotionally involved' with patients. Tschudin (1986), Campbell (1984), and Brykczynska & Jolley (1997), are just a few of the writers who view the emotional engagement of the nurse as an important element of the nursing care process, and crucial to building patient trust and ultimately may contribute to patient recovery. However, the notion of emotional engagement in the sense of 'feeling for' has been criticised as capable of being sentimental and inappropriate in the context of patient care (Thompson, Melia & Boyd 1996, p. 180). In current practice nurse education and training incorporates elements of counselling and therapy, to encourage greater self-insight on the part of the nurse and to ensure that the importance of appropriate emotional involvement, is recognised. Carl Rogers advises that,

'caring in nursing... involves individuals who are honest and dependable, who are clearly able to express their willingness to be helpful. Within such a caring relationship respect is necessary...empathy, the ability to

perceive the feelings of another and the ability to communicate this is seen as central to the relationship and fundamental to making the caring process explicit and specific. (Rogers as cited by Wilson-Barnett 1994, p. 368)

Based on this understanding of the nurse-patient relationship, it would appear that Laurel Rust, the nurse assistant in the scenario, not only communicated, albeit unconsciously, her dislike or perhaps even disdain for some tasks that formed part of her care responsibilities, but, also failed to be aware of Amy's feelings. Laurel may have failed to truly relate to Amy because she was neither happy in nor suited for the role. Whatever the reason, Amy's angry response and apparently accurate judgement of the situation highlights a type of caring that was at best a minimalist approach and lacking in important aspects of relationship. Bowden (1997, p. 109), like many other theorists, draws on views articulated by Iris Murdoch, to explain and understand the work of emotionally engaged attention as an ethical activity that depends on responsiveness to the unique particularity of another person. She quotes Murdoch:

...the cumulative work of attention that refines our grasp of the dynamic and endlessly complex situations in which we find ourselves provides ethical possibilities for action that outstrip the simplifications of rule-bound moral frameworks. Just and loving attention orients this grasp of situations in ways that enable its practitioners to respond to other persons for whom they particularly are in themselves. (Murdoch as cited by Bowden 1997, p. 109)

Murdoch clearly exhorts the nurse to move beyond the traditional advice of 'maintaining professional distance' or to keep patients 'at arm's length'. A common argument has been that this is necessary for nurses to guard themselves from becoming emotionally drained by the demands of patients. There is a question too of whether too much sympathy can reduce the capacity of a patient to cope adequately themselves in the face of suffering and pain. The well-structured context of clinical nursing care with its established domain of routine tasks and standard expectations does not evoke detached as opposed to engaged, or impersonal as opposed to personal care, but rather, a distinct kind of ethical concern that rides the tension between these conflicting dispositions (Bowden 1997, p. 110). The degree to which a carer manages to maintain a balance between these opposing demands in a given situation may prove a challenging task — especially if the patient concerned is difficult, obnoxious and generally resentful of help, as the following case history shows.

3.10 Managing an Abusive Patient

There has been considerable research focused on the quality of care provided in nursing homes and aged care settings, over the past decade. The majority of carers providing physical and psychosocial care, in aged care setting are predominantly care assistants or aides who have only minimal training or education. They provide care often under stressful working conditions such as shortage of staff or scarcity of resources, and may also be the targets of abuse from patients and visiting family members (Molony et al 1999, p. 539).

Even trained nurses working in wards for physically and mentally frail elderly people have reported contact with psychotic and dementing patients to be a major source of frustration and stress. Incontinence is often endemic on wards and having to deal with unpredictable behaviour, ranging from virtual withdrawal to violent outbursts can be very stressful for nurses (Norman & Redfern 1997, p. 489).

How reasonable is it then to expect relatively unskilled carers to reflect exemplary attitudes of care and compassion, on a consistent basis in such settings? To what extent is it realistic to expect carers, for example, to accept racial taunts, physical abuse and other forms of difficult, obnoxious or abhorrent behaviour from patients? The next case study is drawn from observations in one of the nursing homes visited as part of the selection of the study site for this research. It will reveal some of the problems encountered when caring for patients whom staff perceive as undesirable', and the ethical issues inherent in the care process.

Jack was a 67-year-old man who had some degree of brain damage from chronic alcohol abuse. He was a single man whose main interest involved meeting his drinking mates at the pub and betting on horses. He was transferred to a nursing home from hospital, having survived a severe bout of pneumonia brought on by excessive drinking, poor diet, and spending winter nights without heating. Jack tended to be loud, roughly spoken and prone to swearing when minor things upset him. He told the social worker - Ben - that he didn't have any family, he felt lonely most of the time and his only friend was the booze. While he enjoyed the good food and comforts the nursing home had to offer he had considerable difficulties with the staff - medical and nursing. He believed that many members treated him with thinly veiled disgust, often resenting having to do things for him and ignoring him when possible. He would say, 'I know they think I'm scum, a no-hoper, they don't like my type. They don't think I deserve care, but, it's my life and I have a right to be here'.

Jack demanded respect from staff and became angry and aggressive when he felt he didn't get it. He tended to show little regard for nursing home regulations or routines. He managed to get fairly regular supplies of alcohol from two of his skid row friends when they visited. He also frequently ignored the nursing home's no smoking policy, becoming offensive and aggressive when confronted with these issues. Hygiene was not a priority for Jack, he couldn't

see the point of shaving on a regular basis when he really wasn't going anywhere, and bathing invariably became a combative exercise.

In addition to his alcohol-related brain damage, Jack also began to show signs of dementia, sometimes made evident in displays of aggressive behaviour toward staff. Many of the female staff were frightened of him and felt unable to manage him when in a violent state. Because Jack rebelled against any form of physical restraint, staff often resorted to giving him sedative medication in his food, without his knowledge, when needing to calm him down. This approach to managing his aggressiveness was justified on the basis of reducing the possibility of further offensive and violent outbursts. Jack would usually then sleep for long periods of time, which staff would greet with relief. Whether asleep or awake, Jack drew considerable attention to himself and evoked a variety of responses from staff. Sometimes he was the butt of jokes, a source of humour, and staff would generally greet him with an inappropriate degree of informality. However, staff members were concerned for his welfare and were vigilant in caring for him, often in a minimalist sort of way - ensuring he came to no harm.

This case study presents a number of situations which illustrate ethical dilemmas that arise in the relationship between carer and patient, including issues related to patients' rights, carers' rights and informed consent. The circumstances which have contributed to adverse relationships between all parties involved, required understanding and a commitment to ethical practice to ensure the most effective outcome. Professional practice, particularly in health care, demands that personality difference and personal likes and dislikes should not be allowed to influence or diminish the quality of care delivered to individuals. However, patients are people towards whom nurses are likely to have the normal range of human feelings, some of which may be a source of difficulty or conflict during the process of care (Thompson, Melia & Boyd 1996, p. 17).

Conflicting feelings were sometimes evident in the way staff related to and cared for Jack. He knew they had difficulty treating him with respect yet, they had a duty of care and a duty to act respectfully toward him, whether or not they held him personally responsible for his problems. . The issue here may be that staff needed an opportunity to identify and clarify some of their personal values and the reasons that they found it difficult to give Jack respect. This process may be the basis from which better relationships with difficult and undesirable people like Jack could be fostered. Tschudin (1986, p. 110) supports this view by putting considerable emphasis on self-awareness and knowing our values and ethical principles as critical elements of sound nursing practice.

Tschudin outlines some values that apply to helping in general, which are also identified as characteristics of a caring relationship, some of which have been listed earlier, such as respect and empathy. In addition she elaborates on eight 'major ingredients' – *knowledge, alternative rhythms, patience, honesty, trust, humility, hope and courage* – as

identified by Milton Mayeroff in his work *On Caring* (1972) as necessary for caring (Tschudin 1986, p. 1-9), which are similar to the principles of helping, which she examines later in her exploration of the caring relationship (Tschudin 1986, p. 13-19). Tschudin explains that we care in an ethical sense for another person because they have a need and we share a common humanity. In this sense caring is both a human and an ethical mode of being. It is, however, her more detailed analysis of compassion that is of particular interest here.

Compassion is a feeling of distress and pity for the suffering or misfortune of another, often including the desire to alleviate it (Collins English Dictionary 1998, p. 327). For Tschudin (1986, p. 20), compassion is much more than simple kindness. It is something which we cannot learn or know except through experience and which only becomes part of our way of being when we have experienced hurt or pain ourselves and have been shown compassion by others. In this sense compassion is more specific than caring and it goes beyond the professional duty of care. We may ask, with reference to caring for Jack, whether staff members were simply fulfilling their professional duty, or did Jack get a sense that staff were actually compassionate towards him?

There is little to suggest that carers felt compassion for him, but this is not to suggest that they were not caring. It does however, draw attention to the fact that the individual experiences of carers influence how they respond. In this case carers most likely draw on their professional know-how to deal with Jack but, in reality, their personal experience would determine their emotional responses to him. For example it might be that he reminded carers of very damaged relationships within their own families or circle of friends that have remained unresolved, or that they had no personal experience of dealing with people like Jack. If either situation applied, according to Tschudin's theory of compassion, the carer would be able to exercise a duty of care but might be unable to be compassionate towards such patients, due to their ignorance or as a result of carrying unresolved personal hurt.

According to Purtilo and Cassel (1981, p. 86): 'it is unseemly to have antagonistic feelings towards patients, because it is part of the role of those helping professions to act with compassion ... (it) can be accomplished without necessarily feeling personal affection for patients'. Purtilo and Cassel go on to suggest that it is important for carers to recognise feelings of animosity towards patients so that they are not allowed to affect their professional behaviour. A carer in such circumstances might still manage to provide adequate care for the patient, through the help of trusted colleagues or good team support, even though the nurse-patient relationship may be somewhat strained or distant, rather than engaged.

3.11 An Ethic of Caring

According to Tschudin (1999, postscript) an ethic of caring is a combination of ethics and standards of care, or as cited earlier in this Chapter in the discussion on the practice of caring 'ethics is caring' and 'to act ethically is to care' (Tschudin 1986, p. 15). While this approach seems tautological, earning Tschudin some criticism for its apparent lack of practical guidance to actions (Burnard & Chapman 1999, p. 4), it does however provide a conceptualisation of the relationship between ethics and standards of care with respect to this study. To facilitate the exploration of ethical issues inherent in the process of care delivery as applicable to this study, it is necessary to establish how ethics is conceptualised.

A number of key indicators have emerged from the literature review discussions in Chapters 2 and 3 as core elements of an effective approach to care delivery and by implication to ethical practice. For example, drawing on the discussion of the organic and person-centred models of care discussed in Chapter 2 it was concluded that the patient must always be central to the nursing care process. This expectation is also clearly articulated by the UKCC in their outline of principles drawn from the Code of Conduct which states that registered nurses must:

Be satisfied that each aspect of practice is directed to meeting the needs and securing the interests of the patient or client. (Burnard & Chapman 1999, p. 10)

It would therefore seem to be considered unacceptable for example to give priority to carers needs over those of patients or to be unwilling to review inflexible ward schedules or outdated practices. In the same way it could be concluded that the patients interest to maintain as much control over their own lives with respect to all aspects of care, as proposed by Tom Kitwood in the new culture of dementia care, discussed in Chapter 2 and supported by nursing practice discussed in Chapter 3 would be consistent with this principle of care or expectation of staff.

In another principle the nursing Code of Professional Conduct demands that nurses:

Endeavour always to achieve, maintain and develop knowledge, skill and competence to respond to those (patients) needs and interests. (Burnard & Chapman 1999, p. 10)

With regard to caring for patients with severe dementia, this principle seems to require that carers have and continue to develop their knowledge and understanding of the needs of patients and of the challenges faced by people with dementia in particular. It also demands a

development of skills and competencies pertinent to their role as carers of persons living with dementia, which raises issues relating to the training and development of staff, the implications of which will be explored in the study. In addition to the expectations of the UKCC Code of Conduct the conceptualisation of ethics in the context of this study is also underpinned by five core elements of a value framework for dementia developed by staff of the Dementia Services Development Centre, University of Stirling.

The five core values were identified for the purpose of illuminating the connection between quality, standards and outcomes (Cox, Anderson, Dick & Elgar 1998), and to provide professionals facing day-to-day decisions with workable tools which were relevant and which they could 'own' (Cox, Anderson, Dick & Elgar 1998, p. 6). The five values of the framework are:

- Maximising Personal Control: encourages the patient to be as actively involved in maintaining control over their own lives and environment for as long as possible
- Enabling Choice: encourages patients to express their preferences and utilise their ability to make choices in day-to-day living matters
- Respecting Dignity: recognises the importance of respecting and valuing patients as unique individuals in meaningful relationship with others
- Preserving Continuity: participating in programs and activities that assist with recall and encourage engagement in the current reality of the patient is highly recommended for people living with dementia.
- Promoting Equity: patients with dementia have a right to have their needs respected and be assured that they will not be discriminated against because they have dementia or for any other reason. They also have a right to receive a fair share of good quality and appropriate services. (Cox, Anderson, Dick & Elgar 1998, p. 30)

These values recognise that as dementia progresses it creates growing dependency on the emotional and practical responses of others. It also takes into account that responding appropriately and effectively to individual patients fluctuating and progressive needs is a highly complex undertaking. 'Many factors contribute to conflict, and balancing conflicting interests requires consistent negotiation and re-negotiation' (Cox, Anderson, Dick & Elgar 1998, p. 30). The ethical principles underpinning professional nursing practice and the values outlined above, which are tailored specifically to the needs of patients with dementia, provide a broad framework for considering specified standards of care and for monitoring outcomes in terms of ethical care practices with respect to the aims of this study.

3.12 Conclusion

Addressing the issue of contextual and ethical influences on the quality of care, this chapter initially focussed on a process of defining and exploring the elements that constitute quality of life for people in the advanced stages of dementia. Understanding nursing care and what constitutes 'good' practice was also examined. A skilled, advanced understanding of nursing practice was considered essential, but attention was also given to the potential limits of formal rules and the importance of encouraging the practice of discretionary judgement in actual clinical situations.

Much of the Chapter was devoted to issues surrounding the socialisation of new recruits into nursing practice — for the purpose of understanding how the carer makes the transition from lay to professional carer. The development of understanding of shared meanings within ward culture was discussed as a process central to the learners' orientation and socialisation. The way issues of ethical practice permeate all aspects of care was addressed in specific terms through the scenarios and case studies, as a way of anchoring ethical theory in practice.

It is hoped that through this discussion the factors, which influence carers' ways of surviving personally and professionally, have been clarified, and that this exploration has served to illustrate the kind of reality carers face daily and have to manage as they work to bridge the gap between the ideal and the real world of nursing care for elderly people with dementia.

CHAPTER 4:

Research Design

4.1 Introduction

This research is concerned with the kinds of issues that arise for nursing staff in their approaches to the care of elderly patients living with severe dementia. The study explores how carers, in a hospital ward setting, experience and manage problems that arise in day-to-day practice. From this study an in-depth understanding emerges of the ethical issues implicit in the process of care. The findings of the study are based on an analysis of the work and experiences of twenty-four carers who were willing to be observed and interviewed at work over a period of approximately five months. The data gathered was also enhanced by contributions made through informal conversations with staff; observations of other unplanned activities; opportunities associated with the care of patients; and day-to-day life on the ward generally. An interpretative procedure's style of inquiry, as outlined below, was adopted to explore the research questions.

In this chapter I outline the general approach adopted in this research. I begin by discussing the motives and goals underpinning the study, and then proceed to describe and explain the following components of the research methods used:

- The research strategy
- The process used to select the study site
- The factors that influenced the decision to abandon a comparative study in favour of a single site in-depth study
- The layout details of the study site - Karibu Ward¹
- The staff mix on the ward and their years of experience
- The demographic characteristics of patients
- The methods of inquiry used for data collection, including observations, semi-structured interviews and conversations
- The topics discussed in the interviews
- The elements of data collection employed, including the use of time and event sampling

¹ In the interest of protecting the individual identities of the participants of this study pseudonyms have been used. It is hoped that this strategy will ensure that people and places will not be linked to information gathered and will never be publicly divulged.

- The process of data recording, including some of the difficulties encountered
- The approach taken to data analysis
- The ethical and relational considerations relevant to the research design

4.2 Motives and Goals

The study has emerged from developments over the past two decades in particular. During this time there has been a surge of interest in dementia from both academic and practice perspectives. Family members, social services, health and welfare bodies alike have contributed to the wave of interest. In addition the work of social psychologists and sociologists has challenged the traditional medical approach to dementia, resulting in new understandings and care practices as outlined in Chapter 2. Debate and decision-making continues to focus on a series of critical issues including: gaining access to adequate and appropriate resources; availability and support of suitably qualified carers — both paid and unpaid — and the cultivation of care environments best suited to the needs of patients.

Provision of care for elderly people with dementia has become both complex and multi-faceted. For example, gaining access to adequate and appropriate resources is likely to be perceived as a highly desirable aim and worthy of total and unquestioning support. However, in reality the needs of such patients must compete with those of other groups, such as cancer patients and sick children (who are often portrayed in the media in a more appealing light). The adequacy and quality of the available resources for care of elderly people are frequently a source of dispute and discussion in health, media and political forums. Here the specific concern is not only on standards of care for elderly people, but also how carers are to ensure that best practice standards are met in providing care for the needs of patients.

The motivation for this study is the desire to fill a gap in knowledge, about the contextual and ethical influences on the quality of care for elderly people with dementia. More specifically the aim is to advance understanding of the specific contextual influences and ethical issues inherent in carer-patient interactions, and how the management of these factors contribute to the definition of 'quality care' in theory and practice.

This study is not focusing on some of the currently contested ethical issues relevant to older people such as euthanasia, or resuscitation. Rather, it is concerned with recognising the fact that all carers make critical ethical decisions in daily practice, and on a continuing basis, [such as prioritising their time and use of resources according to perceived needs of

individuals] which impact directly on patient care. In addition, the study is motivated by the desire to bring greater clarity to the nature of the practical tasks carers have to manage on a daily basis, as they work to bridge the gap between the ideal and the real in the nursing care of elderly people with dementia.

This thesis seeks therefore to identify the kinds of practical issues and ethical concerns which emerge during the process of daily care for patients with dementia, and their implications for service improvement, staff development and management methods. It explores both practical strategies that carers employ to sustain a responsible and caring disposition toward patients with difficult behaviour, and how carers perceive and engage in the management of ethical problems arising in nursing practice.

As this study progresses attention will also be directed to what the prevailing understanding of dementia is among carers, as well as what they consider to be essential or appropriate care of patients with severe dementia. Finally, we will examine how the process of carer socialisation influences practice, and how carers feel resource allocation impacts on the quality of care delivery.

4.3 Research Strategy

The questions outlined above, which give direction to the study, focus primarily on the actions of carers and also on how they perceive, prioritise and understand issues that emerge in practice. As a result it was decided that observing what carers actually did and how they did it, was critical to understanding the environment of practice and to answering the research questions. Following a period of data collection it was recognised that some observed practice and encounters between carers and patients were not always self explanatory, and that carers' motives and understanding in approaches to care might be better understood if they were encouraged to articulate these. It was therefore decided to build in opportunities to discuss issues of practice with carers as part of the process of data gathering. This took the form of informal interviews and conversations with carers.

Adopting an interpretive style of research (Bulmer 1984, p. 13), the aim was to provide an understanding of practice and issues emerging from the carer's point of view. This approach to portraying, understanding and interpreting the behaviour and actions of carers has its roots in the social psychological theory of symbolic interactionism. Three basic premises of relevance to our research strategy can be identified in this tradition, in the work of G.H. Mead and Herbert Blumer (1969):

- Firstly, people act and react to other people and objects in their environment on the basis of the meanings that these things have for them.
- Secondly, that these meanings are based on social interaction and communication between individuals.
- Thirdly, these meanings are established and modified through an interpretive process undertaken by individuals. (Schwandt 1994, pp. 118-137)

In addition, consideration was given to the 'naturalistic approach', which is based on the premise that there are multiple interpretations of reality and that the purpose and goal of research is to understand how individuals construct reality in their environment (Polit & Hungler 1999, p. 13). Through the adoption of naturalistic methods of inquiry human interactions and behaviour were observed and explored directly. The primary aim in this approach is to understand 'the human experience as it is lived (Polit & Hungler 1999, p. 13), and to understand human behaviour from the actor's - that is the carer's and patient's - frame of reference (Watson 1988, p. 22).

Drawing on these theoretical considerations, this method of inquiry was considered the most appropriate and best suited to the aims of the research as outlined above. This study then, is concerned with the meaning inherent in interactions between patients and carers as interpreted by myself, on the basis of qualitative analysis of data, from participant observations, semi-structured interviews and informal in-depth conversations.

4.4 Selecting Study Site

In clarifying the aims of this study and the specific research questions to be addressed, it became evident that it would be necessary to engage in an intensive period of observation of carers during the process of nursing elderly people. Consideration was initially given to the possible merits of undertaking a comparative study, based on the selection of two care settings. With this intent, a list of registered care providers was obtained [from Age Concern, Scotland, and Lothian Health Board]. This consisted of 79 registered nursing homes. Two hospitals, which also catered for patients with dementia, were explored in the selection of the study site.

Of the 79 registered nursing homes, 4 catered specifically for patients who were terminally ill, requiring palliative care. 50 homes accepted patients with mild to moderate and severe dementia, 17 of which added the specification 'without behaviour difficulties'. The remaining 25 care settings catered for the needs of patients described as

chronic/convalescent, geriatric and geriatric with mental disorder. The descriptors of these categories were based on the Nursing Home Registration and Inspection Unit, Lothian Health Board, 1997.

Several significant issues emerged from this initial survey. Firstly, while care settings might provide similar services, there were obvious differences in characteristics of places: for example buildings consisting of one, two and three floors. While some homes had dementia units as a defined area within the care settings, others did not make any such distinction. Further, the number of beds within identified dementia units ranged from 3-23, a small number of which were occupied by patients with severe dementia. One hospital catered for 20 severely dementing patients, while the other hospital examined catered for approximately ten patients in the terminal stages of dementia.

In the process of determining where to conduct the study it became apparent that care providers made clear distinctions between patients living with mild/moderate dementia and those considered to have behaviour problems, more often identified as patients with severe dementia. This was a clue to the fact, (which was later confirmed on visiting the selected care site) that patients with 'severe dementia' were perceived as more demanding in terms of carers' time, attention and skills.

4.5 Considering a Comparative Study

Initially it was felt that a comparative study based on the selection of two care settings was preferable for the purpose of meeting the aims of the study. It became evident however during the selection process, including visits to the care settings, that a comparative approach would be inherently problematic for these reasons:

- Given that most units catered for only 3-6 patients with severe dementia it was felt it would have been necessary to include at least three care settings in the study in order to ensure that the sample size was large enough.
- Managing the study across several sites was perceived to pose numerous problems, would add considerable complexity to the process, and to obtain the necessary permission from management and to secure the support of staff in different institutions would cause delay and be time-consuming
- It was noted that managers in nursing homes with small sample sizes were at all times eager to reduce, or keep to a minimum, the number of residents with severe dementia — due to their perceived demands on nursing staff. Had a

small sample size unit been included in the study, this unwritten policy and practice were judged to be potentially damaging to the research in the event of patients dying during the process of data collection.

- Given that the aim of the study was to explore in depth the issues arising for carers during the caring process, it was therefore necessary to maintain flexibility in terms of being available to spend extended periods of time observing carers at work in a specific environment. Importantly, this made it possible to attend social functions and other gatherings, such as Christmas Day and St Andrew's Day celebrations in the interests of data collection.
- There was also the issue of different staff rotation systems to be considered. In some care settings. Carers worked in the units for severe dementia patients for set periods of time, usually three-six months, after which they were transferred to other areas/wards for non-dementing patients. This policy of rotating groups of carers in effect meant that those caring for the patients with severe dementia were less likely to experience some of the challenging aspects of the work to the same degree as those in the role on a permanent basis. Comparing the experiences of permanent carers of patients with severe dementia with those staff members who were part of the rotational approach was unlikely to provide a balanced data base due primarily to the variation in staffing policies as discussed.
- During visits to care settings, as part of the selection process, it became evident from exploratory conversations that encouraging managers and carers to participate in a comparative study would have been difficult due to their sensitivity or unease about their performance being compared with that in other care settings.
- Finally, there was the issue of managing the potential increase in costs, time and travel involved in a comparative study involving several sites.

As a result of consideration of the issues outlined above, a decision was taken to abandon a comparative study in favour of an in-depth study of single selected site.

4.6 Selecting the Study Site

During the process of selecting a site for this research, it became evident that high-level dependency patients or those living with severe dementia were likely to be more demanding, in terms of presenting with complex and challenging problems.

Informed by this insight into the practicalities of how care settings functioned, it was decided that the initial search for a suitable study site should focus on severe dementia patients, and should exclude those living with mild/moderate dementia. (This decision was based on the belief and evidence that many patients continue to live in the community; that patients living with mild dementia usually have a greater degree of ability to care for themselves; and that many have the capacity to exercise their own autonomy in day-to-day decisions with minimal assistance.)

It was on this basis that 7 care venues plus the two hospitals were identified from the list of registered nursing homes, for the second stage of the selection process.

Each of the venues was visited informally, in order to formulate some general impressions and to draw some initial conclusions on the possible suitability of the venues for the study. The aim at this point was to make a selection based on the size of the dementia care setting or unit and the dependency level of patients and their nursing care needs, rather than to make selections based on purpose built homes and/or suitably qualified staff.

In terms of size, it was felt that it would be desirable to base the study in a ward or unit catering for approximately 15-20 patients. This was considered an ideal number that would allow for variety in terms of patients needs, personality types, levels of dependency and the like. This number of patients would determine a staff-patient ratio that would be likely to also provide a range of carers and variation in carers' personal characteristics and approaches to care.

Of the sites visited two appeared particularly suited to the aims of the study. While ultimately only one site was selected, further contact was made with the management of both identified sites (*A and B*), and meetings with key personnel were organised.

A meeting with the manager of *site A*, (which had a less cumbersome organisational structure than *site B*), led to an invitation to spend some time at this venue for the purpose of getting a sense of the residents, staff, daily schedules and challenges for care delivery. I visited the site on several occasions at different times from which it became clear that some of the patients had severe dementia while others living with mild to moderate dementia were coping quite well requiring only minimal assistance. This experience also highlighted some of the specific challenges faced by staff as well as providing some insights into the

significance of factors such as the design, location and layout of the units and the issue of appropriate staffing levels and other related factors. At a follow-up meeting with management it was mutually agreed that in many ways the research could be carried out at this site, but a final decision would not be reached until after meetings with the management of *site B*.

Gaining access to *site B* was much more protracted due to the requirement of meeting with and securing the permission of key personnel at various levels of authority such as the consultant psychiatrist, the area nurse specialist, clinical nurse adviser, ward charge nurse and finally the ward staff.

Following a meeting with the consultant psychiatrist - who had overall responsibility for the Annex which included the proposed study site – I was then introduced to the clinical services manager. We discussed the purpose of the research and how it might be conducted in terms of considering implications for the staff and patients on the ward. It was agreed that a meeting would be arranged at which I would have the opportunity to discuss the proposed research with the charge nurse of the study site. Issues arising in terms of protocols to be observed were outlined. A key aspect of the discussion was the matter of providing ward staff with information regarding the study and how it might be conducted – all of which was dependent upon their approval and willingness to participate in the study.

The charge nurse while not anticipating any problems was particularly eager to gain assurance that staff members would not be expected to spend extended periods of time in interviews due to ongoing staffing issues. This was accepted as one of the conditions of conducting the study. It was also agreed that no observations would take place in patients bedrooms or in the bathroom/toilet areas in the interests of protecting patient privacy. Following this meeting I was invited to meet the staff on the ward (between 1.30 – 3.00pm, which was the overlap time between the morning and afternoon shifts). All staff were invited to attend the meeting at which I introduced myself, explained the purpose of the study, the methodology, why I chose this particular ward and how I saw their participation making a contribution to the research. See details of the information presented in Appendix C – Introductory Statement.

Staff members were invited to take part in the study but it was also made clear that their involvement was entirely voluntary, and that they could choose to withdraw from the study at any time without prejudice. It was also made clear that all personal information, such as names of staff and patients would remain confidential and pseudonyms would be used if and when necessary. Staff members had an opportunity to ask questions as a result of which it was clarified that this was not a comparative study, which seemed important to staff

members including the charge nurse. (There seemed to be a degree of sensitivity around the possibility of being compared with staff in other care settings).

Because not all staff could attend this meeting, another was scheduled to accommodate the night staff in particular at the beginning of the night shift. The same process was followed at this meeting – the information was presented with the opportunity for staff to ask questions or have particular points clarified. While it seemed fairly evident from the discussions in both meetings that staff did not have any objections to participating in the study, due process was followed as agreed in terms of being granted permission to proceed. At a staff meeting a few days later the charge nurse and the staff discussed how they felt and what they understood to be the purpose/significance of the study and the logistics of conducting it on the ward. The outcome of this meeting was the decision by staff to participate in the study, which was conveyed to me by the charge nurse. At another meeting with the charge nurse terms of agreement were articulated and permission to begin observations was granted.

Because this study was primarily focussed on staff and would not involve observing patients in private areas such as bathrooms, or interviewing patients or their relatives for example, it was not necessary to obtain the agreement of the local medical research ethics committee, since authority rested at the local level and was therefore, granted by the consultant psychiatrist. However, as a matter of courtesy (and a commitment to due process) a letter was sent to the committee regarding the research (see Appendix A for a copy of the letter). A response was received confirming that the Trust was in agreement that ethical approval was not necessary and noting that management approval had been granted to undertake the research (see Appendix B for this response).

For reasons outlined above in relation to the needs of high level dependency patients living with severe dementia, it became evident that this *site*, which catered for 20 such patients, was more suited to the aims of my research than *site A*.

Following a final meeting with ward staff at *site B*, terms of agreement were articulated and permission to begin observations was granted. The understanding was that I would spend some time on the ward every day or every other day over the first week, following which I would have another meeting with the charge nurse. The purpose of the meeting was to ensure that the unfolding of my role in terms of my presence on the ward was still mutually acceptable and to review, or iron-out, any possible difficulties. As there were no presenting problems, this site - from now on to be known as *Karibu Ward*, - became the focus of the research. The location, layout, design and other significant physical features of

Karibu Ward, as well as, their implications for care delivery will be presented and discussed in Chapter 5.

4.7 Staff Mix and Years of Experience on Karibu Ward

The staff consisted of 6 trained nurses, 8 enrolled nurses and 10 nurse assistants. It was an all female staff except for the charge nurse and two male nurse assistants.

Table 4.1: Years of experience on Karibu Ward

| Length of Time | 6 -12 months | 1-3 years | 3-5 years | 5 years + |
|------------------------|--------------|-----------|-----------|-----------|
| Nurses | 1 | 3 | 2 | |
| Enrolled Nurse | | | 1 | 7 |
| Nurse Assistant | 2 | | 6 | 2 |

All nurse assistants, with the exception of one, had some nursing care experience before coming to Karibu ward. While two enrolled nurses worked day shifts, the others were night duty staff, having worked on the ward for many years. Work was organised in three shifts as indicated in the following diagram on demographic characteristics of Karibu Ward.

Table 4.2: Demographic Characteristics of Karibu Ward

| Demographic Characteristics | Karibu Ward (female patients) |
|--|--|
| Patients <ul style="list-style-type: none"> • Number • Age range • Length of time since admission | 20 64-89 2 months - 5 years |
| Patient Characteristics <ul style="list-style-type: none"> • Incontinent • Requiring assistance dressing • Non-ambulant • Non-conversant or fragmentary conversation • Requiring feeding | Almost all patients All patients 15 patients 15 patients 5 patients need some assistance feeding |
| Staffing Levels on each Shift <ul style="list-style-type: none"> • Morning • Afternoon • Night • Throughout the day | 1 nurse/4 nurse assistants 1 nurse/3 nurse assistants 3 enrolled nurses 2 part-time domestic staff |

The table above provides a general sense of the dependency needs of patients and the number of carers available on each shift to provide care.

The implications of these levels of dependency will be explored more fully later, for the purpose of understanding the variety of activities that combine to form a profile of a carer's workload.

The ward had a full complement of patients (20) throughout the duration of the study. The turnover of patients on the ward tends to be low. Two patients were admitted to the ward over a three-month period, replacing two patients who died. Approximately 75% of patients were on the ward for three or more years. A small number - four patients - were originally admitted to hospital for psychiatric problems and over the years progressed through the system to Karibu Ward. Almost 30% of patients had spent some time on one of the other three wards in the complex, as dependency levels increased while some were referred from other care settings or institutions.

At the time of the study three patients could walk unaided and two with the use of walking frames, despite feeling a little unsteady on their feet from time to time. Of the remaining patients, three were permanently bed-bound and twelve patients needed assistance whenever movement was necessary such as getting into bed or out of chairs. The implications of patient characteristics as outlined in Table 4.1 and other aspects of care as perceived by nurses and nurse assistants will be discussed in Chapters 8 and 9.

The leader of the team on each shift was a trained nurse. While there was no trained nurse on the night shift, as a matter of hospital policy there was always a trained nurse readily accessible with particular responsibility for a prescribed area or number of wards each night. This nurse catered for patient needs in relation to areas of medication which was outside the jurisdiction of the enrolled nurse.

Securing an adequate number of staff for each shift appeared to be an ever-present challenge. On most days staff were drawn from the hospital staff-bank to make up the quota. This usually meant that the person who came was at least familiar with the hospital or might have had some previous experience on the ward. The least appealing scenario according to charge nurses was their having to rely upon agency staff, with no knowledge of the hospital, the ward or of elderly people, the implications of which will be discussed in context later.

4.8 Methods of Inquiry

4.8.1 Observation

This was adopted as a process for data gathering because, as Field and Morse (1985) argue, this method allows access to both events and information, which may not be discussed in conversations or interviews for the reason that some activities that are common practice and familiar to the interviewee may not seem important or worthy of note (Field & Morse 1985, p. 75). In support of this method, Stoller (1989) notes the tendency of researchers to focus on one aspect of human experience, that is, the spoken word, at the expense of other valuable channels such as smell, touch or sound (Stoller as cited by Savage 1995, p. 17). As already discussed above, participant observation is according to Polit and Hungler (1999), a central element of the phenomenological method of inquiry (Polit & Hungler 1999, pp. 246-247) which allows the researcher direct access to the informant's life, enabling the former to take a particular slice of behaviour and interpret it in context (Boyle 1991, p. 277).

As a participant observer I was able to move about within and between groups of staff to observe interactions, behaviours and encounters between staff and patients in different sub-settings. This allowed me the opportunity to get a fuller picture of all aspects of life on the ward. This approach also made it easier 'to sample sub-settings, events, times, subjects and so on systematically' (Sapsford & Jupp 1998, p. 75), and explore data in greater detail.

Guided by this method of inquiry, the initial task in data gathering was to become familiar with the layout as well as the routines and schedules on Karibu Ward; to cultivate rapport with staff; and to 'be-in-the-world' (Polit & Hungler 1999, p. 246), that is, in the environment of the carers. In practical terms this meant that during the first couple of weeks – (it took that amount of time to meet all carers on the respective shifts) - my focus was primarily on becoming familiar with ward routines, and getting to know staff and patients while engaging in informal conversation with staff when the opportunity presented itself. By the end of this stage, I felt that staff understood and accepted my purpose for being on the ward.

Throughout the second and main stage of data gathering, my attention was focussed on key events and activities in daily carer-patient interactions and the exploration of their significance. For example, it became evident during the early weeks of observations that the rhythm of each day consisted of high and low periods of activity. Preparing patients for meals, serving/feeding patients and bathing/toileting

rounds were times of considerable interaction/communication between carers and patients. These activities formed the basis for some initial data collection. In the same way those times in the day such as late morning and between lunch and afternoon were quiet or low activity times. The nature and degree of interaction between carers and patients during these times was also the focus of data collection. Observational data was also collected from unexpected or spontaneous interactions or encounters between people as well as during special social gatherings and celebrations.

It was critically important in this process that I held 'in abeyance any preconceived beliefs and opinions ...about the phenomenon under investigation' — a process known as 'bracketing' in phenomenological inquiry (Polit & Hungler 1999, p. 247). Blocking out presuppositions in relation to data was greatly facilitated by the guidance of experienced supervisors, as indeed was the next stage of 'intuiting' (Polit & Hungler 1999, p. 247) — remaining open to the meanings attributed to the phenomenon by those who have experienced it.

Observation here was therefore a process of becoming immersed in the phenomena under investigation, and allowing the carers' meaning of events to emerge for reflection, description and analysis.

4.8.2 Semi-Structured Interviews/Conversations

In addition to the use of participant observation, semi-structured interviews were conducted with carers. Since I did not attend staff meetings and was therefore not privy to any discussion of care plans for patients for example, or what carers felt about other agenda items relating to the management and functioning of the ward, it was necessary to find another way of eliciting individual perspectives on aspects of care delivery.

Interview questions were based on numerous conversations, staff-room discussions around certain practices on the ward and issues that emerged over many weeks of observations. The purpose of the interview schedule was to detect the significance of any differences and similarities in the responses of nurses and nurse assistants especially with regard to perceived priorities in care delivery. Given also that staffing was an ongoing issue for team leaders it was deemed important to identify the profile of carers in terms of staff turnover and years of experience, and to explore the motivations for continuing to work with dementia patients. Because the matter of training often seemed a contentious issue with respect to the management of basic nursing duties, I felt it was important to explore whether or to what degree nurses and

nurse assistants felt training and development with respect to understanding dementia was a priority. The overall purpose of the interviews was to gain greater clarity on how individual carers felt about: their work; what they believed was necessary by way of training for the job; as well as discussing issues relating to resource allocation.

The interviews took place on the ward and usually in the staff room. The initial plan was to interview all staff: however, it was not possible to speak with two carers who were away due to sick leave and long service leave respectively.

All responses were recorded in brief in the interview - having become aware that some participants were not comfortable having to write their responses while not having a problem with verbalising them. I then recapped what the person had said at the end of the interview, giving the person the opportunity to change, correct or amend anything I had recorded. It should be noted that part of my agreement negotiated with the charge nurse at the outset was that carers would not be expected to spend long periods of time doing interviews. It was therefore a question of taking the opportunity at quiet times, such as coffee breaks, to talk with staff and because I had tended to be around staff in their breaks, this was not a problem.

The process of interviewing was consistent with the rationale underpinning observations in that it recognised the carer as the only person who truly understands the reality of their work environment. The semi-structured interviews and their apparent lack of structure were based on the belief that dialogue in this context would 'provide a window into the routinely constructed interpretations and habitual responses of each individual' (Burns 2000, p. 425). While the interviews were informal in style and similar to conversations with carers, there were some very clear distinguishing features. Firstly, in terms of my preparation, the questions were formulated over a period of many weeks, and were based on my observations, and a growing awareness of the need to understand what motivated the carers in their work. Considerable attention had been given to formulation of the questions (Melia 1987, p. 191), and all carers were asked all questions. (See Appendix F)

The interviews were conducted in an informal way in the staff room. During individual interviews other staff members often came and went from the room, sometimes spontaneously adding a comment to the dialogue. These occasional interjections usually added emphasis to what the interviewee was saying without necessarily saying anything new or contradictory. This approach did not appear to be problematic in any way for individuals being interviewed. However, I am aware, that had I conducted the interviews earlier in the data collection period, I would probably

have found it disruptive. [At the time of the interviews — 4-5 weeks into the data collection — I had adapted to how staff related to each other, the limited space available to them and how to manage my own needs in the context.]

The list of questions was considered a guide, and was used in a flexible way. For example, some questions were of more interest to some carers and as a result they would elaborate more on their response, while on other occasions a carer's response to one question might flow into the response to other questions. The possibility of this happening is, according to Schatzmann and Strauss (1973, p. 73), a kind of hallmark of the interpretive method. The purpose of the initial questions was to identify the length of time carers had worked on the ward — thus providing some information regarding staff turnover.

The focus then moved to the carer's experience in aged care, either within the other hospital wards or in other aged care settings. This was followed by a number of questions which focused on what carers thought was most important in terms of caring for patients and whether experience and/or training in dementia care was essential to fulfilling the role of carer. Carers were also asked whether they actually chose to work on Karibu Ward or were sent to the ward due to re-allocation of staff throughout the hospital or, alternatively, because it was the only work available to them. There was also a question directed to how staff members felt about working with the patients knowing that they would never get better, and that in fact they came to the ward to die. Finally, consideration was given to what carers thought were priorities in resource management. The responses to these questions will be discussed in particular in Chapter 10 but brief reference will also be made to some responses in earlier chapters on data analysis.

Some conversations were also recorded in note form as important data. This was particularly so where I initiated the conversation for the purpose of getting an update on recent developments on the ward, or where a carer specifically gave me information, or when relevant issues were a focus of conversation during staff breaks. There were also situations when a casual interaction with staff provided an opportunity to glean some insights into more general concerns about the provision of care, which I recorded because of their link to the caring process.

4.9 Data Collection

Before beginning fieldwork, a number of key concepts were identified from the review of the literature on current practices, policies and issues concerning the care of elderly people. *The concepts such as, 'patient autonomy' and 'personalised care' were tentative tags that were initially used as focal or anchor points during the early visits to the ward.*

According to the literature the use of these concepts should be considered the beginning of data reduction. However, after a brief time on the ward these concepts were redefined and replaced, based primarily on increasing exposure to the reality of the systems, routines and relationships that made up life on the ward. The new concepts and categories, which were generated from the emerging data, became more clearly defined through a process of ongoing immersion in the life on the ward. More specifically, new insight and understanding emerged through the repetitive experiences of incidents, words, irregularities and how people said things (Bryman & Burgess 1994, p. 7). See Appendix E for a sample of how data was initially identified and collected and how major themes began to emerge based on observations and the considered significance to patient care of issues arising.

As reflected in Appendix E data was initially collected from observations of the Daily Rhythm of Ward Life which was observed and encountered as a series of subsequent and overlapping routines that were strictly adhered to by the staff. From observations it became evident that nursing care duties dominated the approach to care as well as occupying carers for the major part of each day and as a result prioritising physical care emerged as a major area of focus. Further cross-referencing of data collected based on various scenarios revealed that the management of nursing care duties and adherence to routines were inextricably linked. While the initial data collected was of a general nature, as themes began to emerge – as indicated in Appendix E – attention was focused for specific periods of time on different shifts and on different days for the purpose of establishing an adequate body of knowledge around the specific theme and to check the 'strength' of the evidence regarding particular practices, procedures and ways of relating.

Ongoing guidance and discussions with supervisors ensured that observations were explored and tested for further meaning and where necessary carers were asked to provide understandings or interpretations of observed behaviours in terms of encounters with patients and the purpose of adherence to certain practices. This process ensured that data was consistently explored for meaning, that essential links were made across data collected and when necessary further explorations of data took place.

While not intentionally setting out to adopt the methodological techniques of grounded theory, as described by Glaser and Strauss (1967; Strauss 1987), there were elements in the approach taken, which were informed by the thrust of their work in terms of:

- generating categories as a theory building approach;
- keeping an ongoing analytic record throughout the data collection; and
- looking for supportive and non-supportive data when developing analytical categories.

However, it would be misleading to convey a sense of mechanical adherence to this process in my data collection. While recognising the importance of objectivity and impartiality as a participant observer in the field, in reality the data collection process was not unaffected by the impact of fieldwork relationships, and the researcher's own adjustment to the reality of day-to-day situations. There were numerous experiences, observations and encounters, which did not fall neatly into any code or category, but were recorded as data, to be shared as poignant journal reflections.

As a mature age student I was able to bring a degree of sensitivity to situations in which carers seemed particularly stressed. I also felt I brought the wisdom and insight necessary to facilitate an appropriate assessment of situations which required holding a balanced view of the demanding and sometimes demeaning work and the degree of apparent self-investment of carers in their work with patients.

However, at times it would also have been helpful had there been more time to talk with carers for the purpose of following up on observations or for the purpose of seeking clarifications. At times, due to staff shortages, it was not unusual to be asked to help with feeding patients for example. In practical terms that sometimes meant that I was in a room with a few patients and did not have access to observing other patients during these times which could mean loss of valuable opportunities to observe patient/carers interactions. Since requests to help in this way were not made on a regular basis the overall effect could not be considered to have a significant impact on the outcome of the data gathered or ultimately the study.

4.10 Time Sampling

This procedure involved the selection of periods of time during which observations occurred, based on the fact that 'the time(s) at which data are collected, is a critical element in a research design (Blaikie 2000, p. 31). The initial approach to time sampling was

undertaken in a systematic way, which consisted of visits to the ward throughout the morning, afternoon and night shifts, on six consecutive days. Each of these visits commenced 15-20 minutes before each shift started and ended following a brief time of overlap with the next shift. The aim of this approach was to become familiar with how the ward functioned over a 24-hour period, including how teams went about care delivery. By the end of the six days, daily routines were identified and some initial and general impressions were formed, regarding the factors which seemed to underpin the ebb and flow of activities throughout the day.

The next phase of data collection was a combination of time and event sampling — based on the selection of high activity periods, such as the breakfast schedule and shift changes. Event sampling was undertaken in certain situations where events of interest often emerged over extended periods of time. For example, participating in preparation for social events and social activities for patients (on a number of occasions over a period of three weeks) facilitated the treatment of situations in their entirety rather than fragmenting them into discontinuous segments of behaviours (Polit & Hungler 1999, p. 376). Time and event sampling was balanced and combined during the whole data collection process, for the purpose of ensuring that critical events integral to the functioning of the ward were explored. This ensured that the ‘representativeness’ of observed behaviours was enhanced through consistency in time sampling.

4.11 Theorising and Generalising

This study, which was exploratory, established some patterns using the inductive research strategy, which is ‘an approach to the relationship between theory and research in which the former is generated out of the latter’ (Bryman 2004, p. 540).

This study was concerned with exploring contextual influences and ethical issues inherent in the delivery of quality care for people with dementia. One phase of the research entailed the exploration of care practices of 24 carers based on the work and experience of caring for 20 patients with severe dementia. The bulk of the data collected was derived from observations coupled with informal interviews with staff members in addition to numerous conversations.

Based on the data gathered it is argued in the findings that three distinctly independent but related factors which underpin the approach taken to quality care delivery are: staff training, previous work experience and carers’ understanding of dementia. The latter point

for example is of particular interest in terms of how it contributes to or challenges the concept of 'self' as discussed by Hellstrom, Nolan and Lundh (2005) and/or the concept of person centred-approach care as discussed in Chapter 2 based on the works of Davis (2004) and Basting (2003).

The findings would suggest that carers perceptions of the impact of dementia on the patients was more akin to Davis's 2004 notion of a very real dismantling of the self due to the impact of the disease, that any alignment with the belief that the embodied self involves a pre-reflective level which is not dependent on memory (Kontos 2005). In this study the inductive nature of the relationship between theory and research can be seen in the way observed practices and information gathered from interviews/conversations reveal carers' perceptions of the impact of dementia on the patients and the implications for care delivery and the development of care theory.

The particular method of data gathering and modes of analysis employed in this study were techniques and processes used for the purpose of discovering and generating interpretations of the environment being investigated, subject to the limitations of inductive methods. According to Coffey and Atkinson (1996, p. 155), the task of analysing and theorising requires intellectual and imaginative work on ideas in parallel with the other tasks of data management. 'In an inductive argument, the conclusion makes claims that exceed what is contained in the premises, it promises to extend knowledge by going beyond actual experience' (Blaikie 1993, p. 132). Inductively produced theories are supposed to be free of theoretical preconceptions and prejudices as a guard against contaminating the research.

However, it must be noted that critics of this approach, like Blaikie, have argued that 'inductively produced generalisations must be regarded not only as limited in scope but also as subject to modifications by subsequent research' (Blaikie 2000, p. 179) [Just as concepts were developed at the start of this study it was necessary to subject them to re-definition in the light of further investigations]. These critics recognise the necessity for this, and the elements of subjectivity and possible compromise inherent in this process. As a result it must be acknowledged that the selection of concepts and the decisions on how they are defined and measured, might possibly 'prejudice' the findings (Blaikie 2000, p. 179). Blaikie recognises that researchers have no other option but to compromise the ideals of this strategy and then to acknowledge and articulate the consequent limitations of the method.

In their exploration of research strategy and their concern with developing ideas and theories, Coffey and Atkinson reflect on another problem with the inductive approach. In their view, this method is likely to lead to the collection of more and more observations and recordings, which at best 'will encourage unremarkable and undistinguished descriptions of

social worlds and events, with little or no innovations and development (Coffey & Atkinson 1996, p. 155). Coffey and Atkinson do not seem to see any need to elaborate. While they stress that much qualitative research is characterised by an emphasis on exploration and the generation of new ideas, they make no attempt to establish how inductive strategy actually fails in this regard, but move on to elaborate on the merits of abductive ideas (Coffey & Atkinson 1996, p. 155).

Blaikie's (2000, p. 114) use of the concept of abduction built on the earlier works of Willer (1967), but he stresses the difference in emphasis due to his exclusive application of it within the interpretative approach to social enquiry. Abduction is a strategy advocated as an appropriate method of theory construction in interpretive social science (Blaikie 1993, p. 162), and has therefore much in common with the inductive approach. While this strategy could meet the needs of this research, it does however have serious limitations, which Coffey and Atkinson do not identify or consider. For example, in contrast to the researcher's aim to remain detached and objective in the inductive approach, the role the researcher adopts in the abductive approach is based on very different views. 'These include (being) the faithful reporter, the mediator of languages, the reflective partner, the conscientizer, and the post-modern 'narrative dialogue' (Blaikie 2000, p. 126).

Some critics express reservations about the implications of these roles for social enquiry. Many would no doubt concur with Blaikie's conclusions that these roles could lead the researcher in any number of directions including the abandonment of any concern for theory generation. While the inductive strategy has some limitations, which have been clearly articulated and well debated in the literature, the abductive approach is less well known or understood, and as already indicated, has significant potential to fail the purpose of the study due primarily to the complexity of the researcher's role. It is therefore concluded that the choice of an inductive strategy best serves the purpose and interests of this study.

4.12 Recording Data

Field notes were transcribed, category-coded and filed. These notes included information on the setting of the study; relationships between people; records of conversations, events and activities, as well as the investigator's impressions and observations of life on the ward.

During the early weeks of the study, detailed records were kept, with little apparent discrimination between what was and was not important. However, this approach changed as

familiarity with systems, routines and themes started to emerge; and as the purpose of observations became more refined and focused note taking became more selective.

Field notes also included a log of daily events, which are the most common forms of record keeping in participant observation and other unstructured observational studies (Polit & Hungler 1999, p. 369). A record was kept of activities, conversations and events that occurred during each visit to the ward. In addition, specific aspects from the daily log were identified, which were then analysed or interpreted in greater detail. This process was the basis for synthesising and understanding the data. The observational notes were (so far as possible) objective descriptions of activities and conversations and any relevant dialogues that occurred. Theoretical notes took the form of interpretive attempts to give meaning to specific units of observation. In addition there were two other types of note keeping: methodological instructions or reminders about subsequent observations (Polit & Hungler 1999, p. 368); and personal notes. Personal notes were usually about my own feelings or response to situations, and were also from time to time used to note changes in ward atmosphere.

As I became more immersed in the life of the ward and accumulated increasing volumes of data, it was necessary to adopt a more systematic approach to observations. This included reminders of situations I wished to observe further, or participate in, and the reasons why as well as reminders to identify carers I needed to talk to and why. Apart from recording the response to the interviews mentioned above, the recording function was never performed openly during observations on the ward. I was hampered by lack of access to a computer on site. In addition note taking in an unobtrusive manner presented some difficulties, based primarily on my sense that it was an obvious act that I presumed would be inhibiting to many staff members. I overcame this problem by retreating to the staff room or the visitor's room, which was rarely occupied. This allowed me to make fairly immediate skeleton recordings of activities and conversations.

This task was facilitated by the use of a 'cheat sheet' - a loosely formatted grid that allowed me to jot down key words and phrases to be used for later writing up of field notes (see Appendix D). Where writing required direct quotes or immediate comment, I recorded the incident in full in the visitor's room. This was necessary to ensure that critical elements of some events of interest were not lost or confused in recording, as these sometimes spanned a whole shift and/or beyond. This was particularly helpful when I wanted to record dialogues between staff and patients. These notes were then expanded as soon as possible after leaving the ward. I typed up my field notes at the end of the day for the morning and afternoon shifts and on the following morning for the night shift.

4.13 Data Analysis

Data was collected through participant observation, semi-structured interviews and conversations. Each of the data collection methods yielded different and yet complementary perspectives, each contributing in its own way, to give an even fuller picture of the ethical and contextual factors which influenced the quality of care. Based on a descriptive phenomenological approach, and drawing freely upon Watson's (1988, p. 83) interpretation of the research protocol, the analytical process was accomplished according to the following steps.

Data was read thoroughly to get a sense of the whole. Following this process, data was divided into scenarios as expressed by the carer or as observed by myself, identifying and recording new or emerging meanings as they occurred. The underlying aim here was to identify any new insights with respect to the overall theme. At all times it was crucial to remain committed to phenomenological reduction - the isolation of the pure phenomena (Polit & Hungler 1999, p. 247), in this case the carer's experience. The process demands that the researcher should always be concerned with the essence of the event, and its meaning for human experience. In practice this meant checking that each statement captured the essence of the situation.

Different methods including the use of computer software were employed to create and store data, and generally manage the research process. A word processor was used to record and transcribe field notes, to edit material, to store texts in an organised way, to facilitate the retrieval of data and to keep memos and commentaries on data. As suggested by Fisher (1995, pp. 14-32), some standard features of desktop computing were used to advantage in the general management and organisation of the data. However, some difficulties were encountered in the use of computer programs for the purpose of ongoing analysis. It was found that no single software package was specifically appropriate to the kind of data being analysed; in addition experience reinforced belief that 'blind faith in the technology undoubtedly would restrict data analysis and methodological reflection' (Coffey & Atkinson 1996, p. 166).

Further, as categories of information are built up, computer programs tend to 'fix' those categories, leading to concern that there may be a reluctance to change those categories or reorganise them because they are fixed or set by the program (Croswell 1998, p. 156). The issue of 'fixing' categories was a significant concern in this study from the start, since it had the potential to decontextualise data and, in doing so, to lose the 'spirit' of actual interaction and encounters, which in turn would diminish the perceptions and understandings of carers'

reports. At the outset, the NUD*IST program, with its potential for generating categories and building on themes, was considered as a resource to facilitate the process of analysis.

However, it was found in this study that the program was more suited to the management of large volumes of data and its use was time consuming, requiring advanced knowledge and skill. On this basis, and possessing only a moderate proficiency with the program, I decided not to rely on this approach as a primary mode of analysis.

4.14 Ethical and Relational Considerations

As in any social research the major ethical issue is related to the treatment of human respondents or participants (Blaikie 2000, p. 20). Procedures were put in place at the outset of this study to ensure that all participants were fully aware of the nature of the study, what was expected of them and how their anonymity would be assured, as well as to give assurance that any information they provided would be treated in confidence. It was also agreed that only pseudonyms and not staff or patients' names would be used. It was also important that the 'open' and 'closed' settings (Lofland & Lofland as cited by Lawler 1991, p. 12), (i.e. areas I did and did not have access to), were clearly defined and known to all carers. For example, respect for the privacy of patients required that I did not observe in private areas such as bathrooms or in bedrooms while patients were being dressed or nursed. This did not pose a problem, as all but three patients spent the whole day in the sitting rooms and therefore provided ample opportunity for observations.

While abiding by these clearly articulated and mutually agreed guidelines, all interactions were conducted in a spirit of trust, respect and professionalism. My rapport with carers was evident in their willingness to include me in conversations and the 'banter' typical of staff rooms, as well as in their readiness to answer my questions in a straightforward manner and provide me with opportunities to gain experience. Given my previous knowledge of health care and experience of health care settings, as a 'native' of hospitals (Schwartz & Jacobs 1979, p. 48-49), it was relatively easy for me to fit into the ward environment and to engage with staff on issues relating to aspects of life on the ward. I felt staff members were relieved to know that I came with some knowledge of hospital life, while also feeling 'relieved' that I did not come with an expert knowledge or experience in their specific area of work with elderly patients. There were also times when I was aware that as a mature-aged female researcher, I seemed to blend rather easily into the environment, as many of the carers were women around my own age.

As a participant observer, I deliberately did not take on an existing role on the ward, although, as mutually agreed at the outset, I did occasionally help out when needed with feeding patients, accompanying them in the corridor for safety purposes or similar tasks. I also engaged in and assisted with extra-curricular activities, - an approach reminiscent of the Woods (1979) study in the late seventies, in which the researcher perceived himself as 'involved' rather than a participant observer.

It should also be noted that the extent of my contribution in terms of giving practical help was limited by ethical and legal considerations, since I was not a nurse nor trained carer. I restricted myself to practical tasks and activities that posed no risk to patients. In addition to guarding against the possibility of staff becoming dependent upon my assistance at any point, I chose to avoid any tendency towards adopting a routine or appearing on the ward at set times. While, as a matter of courtesy, I always informed the person in charge of the respective shifts of the general time of my next visit, there was never any problem. After the first couple of weeks my presence there was simply assumed.

While staff were very co-operative and did not seem to be self-conscious in my presence, it had to be recognised that there was always the potential danger that as the researcher I would be viewed with suspicion — 'as an inspector or critic, an intruder or snoop' (Sapsford & Jupp 1998, p. 75). It is important to mention that some staff were friendlier than others. This seemed to be primarily due to the degree of contact I had with them — i.e. having less time with part-time or bank staff. However, there was no evidence to suggest that their behaviour changed or that they presented themselves in a guarded or particular way due to my presence as a researcher. For reasons already outlined, this did not appear to be a problem in this study. There was no evidence of hostility towards my presence or role at any time.

CHAPTER 5:

Ward Layout, Furniture & Equipment

5.1 Introduction

This chapter is concerned with the physical features of the study site, as a significant factor in care delivery to patients. Discussion in this Chapter will include:

- key characteristics of the study site and its location and relationship to other buildings on the hospital complex
- a description of the key features of the layout of Karibu Ward, including the allocation of spaces for various activities such as sleeping and communal gathering
- an identification of issues associated with shared facilities
- an identification and discussion of the factors emerging from limited access to quiet and personal space
- the absence of quiet areas for individual patients and adequate spaces for social gatherings
- a description of the nature and quality of seating and mobility devices and their implications for carers and patients
- a description of elements of the ambience and orientation of the ward and the wellbeing of patients
- a brief outline of the staff room as a feature of the ward

5.2 The Physical Environment

Since the needs of older people have emerged as an area of speciality, including those living with dementia, several factors have been identified as critical elements to be considered in the delivery of care. As already discussed in Chapter 1, many recent studies stress as a key feature the need to take account of the impact of environmental factors in the provision of care for older people. This emphasis on the physical aspects of care has been well developed in recent years in relation to the treatment and understanding of people with dementia in particular. There now exists an abundance of advice on how to create an

appealing and therapeutic atmosphere for patients through careful design of buildings and appropriate choices in furnishings and equipment in the care setting (Goldsmith et al 1997).

It is believed that the physical environment has a pervasive effect on the well-being of patients in long-stay care (Denham 1997, p. 231). Greater sensitivity to the importance of the physical and social environment in relation to the health of residents/patients has become a key feature in the design of residential, hospital and other aged care settings over the past decade in particular. With regard to building design, an international consensus is now available on good design for dementia care, paying specific attention to the disabilities of patients for the purpose of planning the environment to compensate for their needs (Hooper & Parker 2000, p. 102). Based on an exploration of how the environment affects older people, Lawton states 'that as an individual's competencies decrease, the environment, both physical and psychosocial, and the effects of environmental pressure become more important' (Rader 1995, p. 47).

It has also been stated that however accommodating a chosen care setting and its staff may be, it must be recognised that 'at a moment in life when they experience multiple loss and start to acknowledge their own vulnerability, residents must adjust to this unique amalgam of physical strangeness, unanticipated routines, an unfamiliar peer group, and a set of formal relationships with staff - all provided in a rule-bound world' (Willcocks, Peace & Kellaheer 1988, p. 140). Willcocks et al go on to observe that these are features of institutional care which have not been obliterated despite deliberate attempts to do so. It seems reasonable to suggest however, that since the publication of their work, much thought has been given to how the 'provision of appropriate furnishings, equipment and décor can not only improve the lives of older people living in nursing/residential homes or long-stay hospital wards, but may also enhance the working conditions of the staff' (Denham 1997, p. 231).

As a strong advocate of this perspective, Marshall (1997) lists design and furnishings skills among those considered important in an ideal workforce. She also stresses the importance of 'recognising the way in which particular physical features of the building may affect the wellbeing of the person with dementia, for example positioning of mirrors, ease of access to the lavatory, individualised environments which reflect preferences, lighting, colours and textures' (Marshall 1997, p. 114).

It is against this backdrop of current thinking, on the importance of what constitutes an appropriate environment and how it impacts on patient care, that attention will focus on the setting in which this study was carried out - Karibu Ward.

5.3 Key Characteristics

Karibu Ward is one of four wards forming an annex of a long established mental hospital, which has major teaching and research units, specialised units, facilities for day patients and community services. The four wards forming the Annex were opened in 1982. They cater for the needs of 80 psycho-geriatric patients - 20 patients to each ward. The wards are usually described according to certain attributes of the patients in them, and are thought of in terms of a graded hierarchy. At the top of the hierarchy are two wards in which almost all the patients are ambulant, able to converse and reasonably self-sufficient. Below this is another ward in which these attributes are less common and patients require more assistance. Finally, Karibu Ward, located on the second floor of the building, caters for the needs of the 20 most deteriorated, confused, dependent, non-conversant, mainly non-ambulant and incontinent patients.

The turnover of patients on Karibu Ward is low and while transfers occur to the ward, patients are usually not transferred from the ward - remaining there until they die. As indicated above, the attributes of patients on Karibu Ward are thought of in terms of a graded hierarchy from relatively independent to those who are very dependent. Because patients usually 'graduate' through these wards to Karibu, the latter tends to be described as 'the last stop' or 'the end of the road', conjuring up a sense of helplessness and hopelessness in the minds of carers in particular.

5.4 Layout and Furnishings

KARIBU WARD



EXISTING FLOOR PLAN
NOT TO SCALE

Figure 1: Layout of Ward

The layout of the ward is L-shaped (Figure 1), - one arm consisting primarily of 4x5 bed dormitory style rooms, which cater for the 20 female patients. Each patient has her own bed with a locker and a very small wardrobe for personal belongings. The other arm of the

ward - the day area - consists of several small sitting/dining rooms in addition to utility rooms, bathroom, cupboards and two small offices. One office is for the use of the ward charge nurse and the other is usually used for handovers, staff meetings, report writing and other administrative tasks. In addition there is a small staff room and a family/visitors room linking the two arms of the ward. At the point where the two arms of the ward meet, some easy chairs and a television are positioned, forming a natural meeting point for staff and patients. The entrance door to the ward, which is in the day area, is kept locked at all times as is the exit door at the other end of the ward.

In one of the bedrooms there are three permanently bed-bound patients. Apart from these patients a clear separation is maintained for the others between day-time living and sleeping areas. All other patients are transferred from the sleeping area each morning and congregate in the sitting rooms. This facilitates the task of supervising patients. In the sleeping area patients have very little personalised space in terms of bed space, however, a few do have family photographs and small ornaments over their bed or on their lockers - small reminders reflecting patients' identity and individuality. Patients do not bring in pieces of their own furniture, as is the practice in some care homes. They are at all times dressed in their own clothes, which are well maintained by carers. In general the sleeping area tends to resemble a standard hospital ward rather than shared personalised bedrooms due mainly to the fact that large glass windows separate the rooms from the corridor, allowing for patients to be observed, but affording little privacy.

The corridor and communal spaces in the day area are subjected to a lot of activity and traffic. As a result, carpets and coverings are showing signs of wear and evidence of spills that cannot be removed. However it is evident that some attention had been given to creating a welcoming and homely environment in the past. The walls are painted in soft colours, curtain fabrics are pleasant to the eye and the walls in the corridor are adorned with a few pictures of colourful floral arrangements and country scenes. The sitting and dining rooms are sparsely furnished. For example one sitting room has a television and a small table and the dining room has several tables that seat approximately five people. There is no space for other furnishings because care has to be taken to ensure that there is always enough room to mobilise patients. Due to the number of patients and the bulky size of some mobile chairs the sitting rooms tend to look crowded most of the time. Again there is no personalised space in these areas.

As already mentioned, the ward is located on the second floor of the building. The windows of the day area are relatively small, preventing patients from admiring the views when seated. Patients are thus visually deprived, never seeing trees, flowers, sunshine or

rain. Again, because the ward is located on the second floor, taking patients into the garden is not considered a feasible option — due to the considerable drain it exerts on staff time and energy. Having access to outdoor spaces and the sensory stimulation of visually pleasing sights and scenes, has considerable therapeutic value and comfort for patients (Randall, Burkhardt & Kutcher 1990; Archibald 1997), - an important factor that has not been catered for in the design and location of Karibu Ward.

Throughout the day staff interactions with patients take place mainly in the sitting/dining rooms, making it convenient, from an observer's point of view, to hear and see what is going on without being intrusive as a researcher. This was particularly so at mealtimes, since I sometimes got invited to assist (and at other times offered to assist) with the feeding of patients. Other observations were undertaken from the open lounge space identified in the floor plan, where people tended to congregate during the day.

5.5 Shared Facilities

The design and layout of Karibu Ward is in strong contrast with many of the modern purpose-built units, that are based on more up-to-date understandings of dementia care. Given that the ward was opened in the early eighties, its design was most likely the work of architects whose prime experience had been the design of traditional hospital wards. Because the ward's designers did not have the benefit of knowledge of research on dementia care over the past 15 years, the ward was set out in the traditional pattern.

Patients share sleeping quarters as well as dining, washing and toileting facilities. While carers do seem to be particularly vigilant in guarding the privacy and dignity of patients at all times, these communal aspects of ward life can make it more difficult to uphold required standards.

For example if a patient had access to a toilet in their room or shared with one or two other patients, greater privacy could be ensured and a more personalised approach facilitated. 'A personal toilet and shower give humanising space, elevating the status of the resident to that of a private individual' (Mulley 1997, p. 231). While care is taken to ensure that unpleasant odours are eliminated as much as possible, patient toilets are situated close to the main entrance to the ward. This means that relatives to the ward might be 'assailed at the door by pungent smells of urine or faeces' (Jenkins 1999, p. 15). Nor is such an inviting environment in which carers have to live and work throughout the day, as Jenkins affirms.

The location of the toilets appeared therefore to be problematic with respect to patient privacy.

5.6 Lack of Space

Attention must also be drawn to the fact that the layout of the ward, allowed no space for provision for programmes or activities for patients. During my orientation to the ward reference was made with some enthusiasm to the fact that an occupational therapist would be available to work with patients on the four wards in the Annex. However, throughout the duration of the study no further reference was made to occupational therapy, nor was there evidence of programmes or activities at any time. While this issue will be considered later, attention is drawn to it in this context because again in terms of space, no provision is made on the ward for programmes or activities. While it could be argued that patients could be taken off site for activities, this would be a very labour intensive exercise, raising other issues regarding staff availability and therefore is not likely to receive much support.

Finally the issue of space is particularly problematic on special occasions, such as the St Andrew's Day party and similar events, when relatives of patients are specially invited to attend. Apart from the fact that there is very little space to seat relatives next to the respective patients, it very often proves problematic because patients are positioned too close to each other. When this occurs, some patients become disruptive, grabbing arm-rests of chairs and items of clothing and generally creating a disturbed atmosphere by pushing and pulling at other patients and/or their relatives. Some aspects of these occasions were energy-draining and caused anxiety for staff in particular, requiring a lot of effort and often ending in patients having to be removed from the event.

5.7 Seating and Mobility Devices

Chairs used by patients on the ward are not standardised nor of uniform height, but neither are they customised for individual needs. There is available a variety of chairs of different sizes and shapes, but a few patients have their own chairs provided by family members. While the easy chairs provided are reasonably comfortable, many patients frequently appeared restless when seated, and found it difficult to get out of deep-seated chairs without assistance. Chairs had plastic covers and were therefore easier to clean. This

is an understandable choice, but fabric covers would be less 'institutional' in appearance. Similarly, vinyl floor coverings are provided in the bedrooms, (instead of carpets which can give a more homely feel), because they are easier to wash and maintain. There are numerous other examples throughout the ward, which reflect pragmatism in choice of equipment and modifications, sometimes at an apparent cost to patient identity, dignity and individuality.

Encouraging independence and promoting mobility are all key features of current thinking on ways to improve dementia care. The majority of patients on Karibu Ward are chair-bound, while a few shuffle up and down the corridor scores of times throughout each day. What was not entirely clear was the actual capacity of those who remained seated. There was no evidence of carers spending time encouraging patients to walk or exercise a little nor was mobility promoted through the use of zimmer frames or walking sticks. Patients did, on many occasions, attempt to get out of chairs but were usually encouraged to sit back and remain seated for fear of falling. From observation it was evident that the immobility of patients could have been better addressed, in part at least, had there been some basic equipment available and time committed to ensuring that their failing capacities were not further diminished or lost through failure to exercise.

The quality and use of hoists appears to be fraught with problems for carers and patients. The hoists in use on the ward were cumbersome, unsteady and outdated. Carers complained regularly about the difficulties associated with the highly risky manoeuvre of lifting a patient out of their chair and into a bath. Difficulties arise from the limitations of the equipment to lift patients with ease, and also from the fact that hoists are designed to be operated by two people rather than one — as is the practice on the ward. While there is now an increasing variety of hoists available on the market - some electrically controlled, others battery powered - those on Karibu Ward are manually operated and their safe use very dependent upon the skills and strength of the carer. The task of lifting and transporting patients is made more difficult and risky for carers using the presently available equipment and for patients means undignified handling.

5.8 Ambience and Orientation

One of the most striking features on entering the ward is the noise level from television sets, telephones and the general interaction between people. This seems to reach a peak several times throughout each day but especially at mealtimes and during change of shifts. At these times staff sometimes become anxious or upset, particularly if they are

getting behind schedule; if the correct meals are not delivered; if patients are disruptive; or if somebody fails to turn up for work. It is these kinds of factors that tend to create a mood of agitation and restlessness on the ward.

It would appear that carers become desensitised to the noise, and as a result no attempts are made to give consideration to reduction or its possible negative impact on patients. Some noise pollution could be eliminated by turning off the television and radio from time to time, especially during quiet times and at night, or by playing music and relaxing tapes of the patients' choice, to create a more relaxed, calm environment.

One of the key aims in designing specialist care centres for people with dementia is to ensure that their difficulty with orientation can be reduced as much as possible through effective design. So, 'the design principle of immediate visual access is crucial' (Archibald 1997, p. 38). In practical terms that means providing cues, landmarks and signs that will make sense to patients and above all help them to find their way around. For example, on the ward, the toilet door is identified with a sign but the door is the same colour as every other door on the corridor and therefore perhaps not so readily identifiable for a patient who is disorientated or poor-sighted.

Unlike the practice in some care centres, patients on Karibu Ward do not have any identifiable cues such as a name or photo above their beds. Since food is not prepared on the ward, patients are deprived of the use of the sense of smell from freshly brewed coffee for example or aromas from other foods. However, it is difficult to assess the real impact of these examples on patients since they tend to stay in one place and when they move, they are always accompanied by carers to and from the sleeping area, the toilet, the bathroom and dining rooms. As a result, they do not have to exercise the usual skills required to find a place such as the toilet, which may in effect result in this skill being lost if it is not used. The issue of encouraging independence and tolerating reasonable risk-taking as important aspects of patient care, will be discussed in later chapters.

5.9 The Staff Room

The staff room is a converted single bedroom, consisting of a collection of mismatched easy chairs, a small hand-basin, table and a wooden shelf. Because the majority of carers smoke in the room - the only space available on the ward - all are subject to the lasting smell of cigarettes, which proved objectionable for some individuals. The table and shelf always seem chock-full of mugs, an assortment of tea/coffee boxes and a variety of odd

jars. In summary, the room is an unattractive and unappealing environment in which to relax, and little care is taken to create a hospitable atmosphere. While the location of the room allows carers to supervise patients in the corridor and observe activities it provides little opportunity for carers to take meal/coffee breaks or to get away for a brief time from the pressures of the ward. The poor quality of the staff room - the only accommodation available to staff - seems to reflect the traditional view of care, that it is focused on patients only. Over the past decade significant emphasis has been given to catering for the needs of carers as well as those of patients (Archibald 1997, p. 21). The degree to which this was evident on the ward will be discussed further in the discussion on the influences of environmental factors in Chapter 7.

5.10 Summary

Given that Karibu Ward is part of a very large hospital, which has major teaching and research facilities as well as being a primary training base for medical, nursing and paramedical staff, the ward does not seem to benefit from the availability of a wide range of professional skills or sophisticated physical treatment facilities. In fact the ward is quite traditional, particularly in design and staffing patterns, and these impact on how care is delivered.

Regarding the layout of the ward, it could be described as quite compact from the carer's perspective. In the absence of emergency call buttons or bells, typical of more acute care settings, it is still possible to get back-up support very quickly when critical situations arise. However there are aspects of ward layout that militate against patient privacy and individualised approaches to care. These will be explored in Chapter 7.

The position of the ward on the second floor of the building prevents patients having any contact or access to the external environment. The need for sensory stimulation in terms of visually pleasing sights and scenes appears to have been overlooked in the design of the ward. This deprives the care environment of a potentially therapeutic element and a valuable positive dimension of care for patients. It also reduces the appeal of the ward as a pleasing work environment for carers.

The provision of good physical care is considered a priority and this is reflected in the attention given to patient comfort, safety and due attention to bodily functions. However, the fact that patient toilets and the bathroom are situated just inside the main entrance to the ward makes it particularly difficult to ensure privacy in these most intimate aspects of care.

The design of the ward in this regard requires that patients be transported down or across a fairly public corridor used by visitors as well as all carers and other patients. As already discussed the position of the toilets close to the ward entrance can be offensive to visitors, given the potential of being greeted by unpleasant smells on entering the ward. In relation to design, Goldsmith et al point to findings that support the view that the more attentive and sensitive we are to the needs of people with dementia and the more we ensure that care environments are relaxed and secure, the more likely it will be that patients will be able to communicate more effectively (Goldsmith et al 1997, p. 28).

The necessity for and merits of patients having some private space to withdraw to on occasions — just to be alone or to remove themselves from an aggravating environment — seems to have been overlooked in the design of the ward. Patients are therefore subjected to communal living at all times without choice or relief. This conflicts with a growing body of knowledge that suggests people with dementia are individuals with personal preferences and wishes, the same as other people (Kitwood 1997).

In addition, no provision has been made on the ward for spaces in which to conduct programmes or activities for patients. The ward is evidently designed to cater for the physical care of patients, communal living and their constant supervision, but fails to provide for a recreational or therapeutic dimension to care or for the needs of carers. This strongly suggests that care is designed according to a limited medical approach to care, with little evidence of recognition of the importance of the psychosocial elements of care.

CHAPTER 6:

Care Delivery on Karibu Ward: Practicalities & Priorities

6.1 Introduction

This chapter is concerned with day-to-day life on the ward and with how carers experience and manage problems that arise in the process of care. Recognising the fact that all carers make critical decisions on an ongoing basis, such as prioritising their time and use of resources according to perceived patient needs, this chapter is concerned with key themes that emerged from observations of carers at work.

In relation to the following record of a day on the Karibu Ward, only brief reference will be made to each theme to emerge from observations during the early weeks on the ward. Before exploring each theme in more detail, an account will be given of the daily programme of ward life, for the purpose of setting the scene from which the themes emerged. The account will begin with the handover from night staff to those beginning the morning shift. The report will then progress through the events of the late morning, into the afternoon and including elements of the night shift.

In this chapter discussion will be directed to the following themes:

- how patient care was routinised and the implications for care delivery
- the prioritisation of physical care as a dominant feature of nursing practice
- issues of communication between patients and carers will also be explored
- attention will also be directed to the impact of the building environment on patient care
- issues underpinning the effective management of patients with challenging behaviour will also be discussed.

The focus in this study has been on what carers actually did and on how they did it (i.e. what care practices they adopted).

6.2 Themes Identified

As already indicated, certain aspects of the design of Karibu Ward seemed to have a significant bearing on how patients' needs were met — e.g. the way patients were supervised

and the degree to which communal living was a 'given' rather than an option for patients. The actual and/or potential impact of the ward layout on the delivery of care, was never identified or alluded to by carers as a problem at any time during the early weeks of interacting with them — with the exception of their expressed dissatisfaction with staff amenities. Carers' apparent lack of insight into the relationship between themselves, the patients and their environment led to environmental influences being identified as a key element to be explored in relation to patient care.

An important feature of ward management and the delivery of care was staff adherence to the various daily and weekly schedules that served to define and ensure the delivery of care. How routines were sustained and for what purposes was a key theme in this study. The function of routine in ensuring consistency in approaches to care delivery, as well as the implications for carers and patients were also studied. Connected to this were regularised care practices, an obvious commitment to cleanliness, maintaining order on the ward, and, an emphasis on the physical care of patients. Having its roots in traditional nursing practice this last mentioned aspect of care was identified for further exploration in relation to the specific care needs and problems of people with severe dementia.

Initial observations on the ward highlighted the particular communication difficulties and limited capacities of the patients to articulate their needs. In addition the fact that carers received relatively limited training with respect to these specific needs of patients led to the identification of communication as a critical element of care for consideration in this study. Finally, carers' attitudes to and understanding of patients who engage in disruptive or disturbing behaviour was recognised to be foundational to the appropriate management of such patients. Initial observations of carers' methods of managing challenging behaviour, highlighted the complex issues associated with this aspect of patient care and the skills needed to manage such situations appropriately. Managing patients with disturbed behaviour was therefore identified as one of the five themes to be analysed in later chapters.

By way of establishing the relevance of the themes identified above from observations of carers at work, some extracts will be presented from extensive diary notes resulting from the first few weeks of data collection. These descriptive accounts are intended to profile life on the ward, while providing some insight into the relationship between the characteristics of the ward environment and the behaviour of patients and staff, as well as the rhythm of life and levels of activity. The aim is to present the flavour of real life on the ward, based on observations, by reflecting the full range of events that occurred for the purpose of exploring their relevance and influence on the quality of care for the patients with dementia. It is from these and other observations that the identified themes emerged.

This account begins with the handover from night staff to those beginning the morning shift. The report will then progress through the events of the late morning, into the afternoon and include elements of the night shift.

6.3 The Daily Rhythm of Ward Life

6.3.1 The morning shift

On entering the ward, one was immediately met with a wave of stuffy air - a mixture of heat, air freshener and the very distinct smell of incontinence. It is understandable that one's first thought or reaction might therefore be 'how can people work here?'

It was 7.a.m, and, with the exception of the person responsible for the handover, carers from the night shift were ready to go off duty, while those on the morning shift were arriving to start the day. The handover briefing was given in the staff room, involving only the two people giving and receiving the report, which lasted about seven minutes. The report consisted of brief general comments about a few patients, with specific reference to one patient who had fallen out of bed during the night, incurring an injury. Following the handover, other carers assembled for the morning shift and were given instructions regarding patients in their care. The hierarchical nature of the nursing team was evident through this brief activity of handover management — a point which will be explored more fully later.

Following some discussion, based on the management of patients and the allocation of staff members to colour coded working groups, the work schedule for the morning began. Working in pairs, carers disappeared behind screens in the patients' sleeping area. Assisted by their carers, the patients' day, which was set in a series of time-patterns, began with getting up, being washed, toileted and dressed. These tasks were undertaken with minimal verbal interaction between patient and carer, aside from brief instructions from a carer to encourage the co-operation of the patient.

At one point the subdued atmosphere was broken by a rather sudden altercation between a patient and a carer. The former refused to get out of bed, and the gentle encouragement of the carer led to an aggressive outburst by the patient who slapped the unsuspecting carer hard across the face. Having been taken completely off-guard the carer quickly left the room in shock, and made her way to the staff room, clearly upset and angry.

Meanwhile, in the bedrooms there were discoveries made of soiled beds, and soiled patients, which delayed and diverted some carers from their desire to get the job done on time. At approximately 9a.m, the first migration of patients was assisted to the dining rooms for breakfast. While some patients found their own way with the aid of walkers, others were moved in wheelchairs - all seemed to arrive for breakfast with a degree of precision. The daily movement of patients *en masse* to the day area meant that there was a clear distinction drawn between that area and the sleeping quarters. The latter were largely deserted throughout the day with the exception of the nursing care activities related to three bed-bound patients who lay motionless, curled up in a foetal position or staring at the ceiling.

Back in the day area breakfast was served, and the noise level rose due to the clattering of dishes and some minor incidents of disruptive behaviour from a few patients. All carers assisted with the serving of food and the management of patients during breakfast. The meal consisted of porridge, which patients managed to swallow without difficulty, followed by marmalade sandwiches - served without plates - and a cup of tea from a very large communal teapot. The charge nurse was primarily engaged in administering medications at this time, which in practice meant the four nurse assistants had to feed twenty patients. They tried to share out the slow feeders and to hurry those patients who tried to feed themselves.

It became evident from the course of events up to this point, that synchronisation of activities and sticking to time schedules was not only in the interests of staff, but also of particular significance to patients. If carers were, for whatever reason, thwarted in their efforts to have patients in the dining area by 9 a.m. breakfast was likely to be cold — having remained on a food trolley in the hall since being delivered from the hospital kitchen in the next block some time earlier. Breakfast was served in haste and patients were encouraged to hurry, because of the pressure to ensure that all breakfast dishes and cutlery (spoons) were returned to the trolley on time, for collection by kitchen staff.

After breakfast, patients remained in the sitting rooms, while carers had their first break of the day in the staff room. One patient who was partially blind wandered into the staff room but was removed with an instruction to stay seated in the lounge area until breakfast was over. This conveyed the feeling that there was really never any down-time for staff, that is, time away from the patients, as they do not leave the ward at any time for meals or coffee breaks.

Following the staff breakfast, patients were toileted and transferred back to the sitting rooms. This exercise, which was undertaken by individual carers and facilitated by the use of some antiquated lifting equipment, led to a great deal of shoving, pushing and pulling of patients. It drew attention to the obvious discomfort of patients; this was a concern for carers who repeatedly remarked on the consequences of using low standard equipment. Following the toileting of patients, nursing staff made beds and disposed of soiled sheets into laundry bags ready for collection. A member of the domestic staff then vacuumed the corridor and sitting room and cleaned the floor in the dining area and dormitory. The television (TV) was left on in one of the sitting rooms, but nobody seemed to notice the deafening volume as patients were arranged around it, supposedly watching a chat show. Out in the corridor, a few patients wandered up and down, while carers continued to attend to bed making, cleaning and tidying the dormitory area.

In another sitting room down the corridor, where all the 'noisy' patients were congregated behind a large glass window, there was a constant rhythmic wailing, screaming and calling for help or attention. The repetitive nature of the noise was quite aggravating at times, creating a somewhat distressing atmosphere for patients and staff. The wailing voices demanded attention, and staff managed this situation by observing the patients from the corridor through the glass window as they walked past, while keeping up the momentum of the morning routines. By 11 a.m. the noise seemed to abate somewhat and carers emerged almost in unison from various rooms for a short break. The conversation over coffee and cigarettes was primarily focussed on the carer who was upset earlier. Her obvious hurt and embarrassment was defused by the use of humour, reflecting the bond between carers in time of need and the use of humour as an effective 'survival' technique.

The charge nurse joined the group for the purpose of sorting out an urgent staffing issue. A nurse assistant on the afternoon shift had called in sick, but no staff member present seemed willing or able to help out. The charge nurse promptly disappeared to the office to make phone calls in pursuit of help elsewhere. It also emerged from the conversation that one of the nurse assistants on the afternoon shift was an 'agency' nurse and had no experience of the ward. This situation drew gasps of sympathy for the charge nurse who was also in charge of the afternoon shift. As the discussion on staffing issues continued it became evident that regular ward staff resent having to bear the greater burden of the workload, because their co-workers — bank or agency staff — are unfamiliar with the work, the routines and practices on the

ward. The many facets of this issue will be explored more fully later, including the flow-on effect for patients.

Leaving the charge nurse to worry about staffing the afternoon shift, carers returned from the coffee break to engage with the patients, many of whom were more alert now. Some needed to be changed or propped up in their chairs in preparation for morning tea. As staff and patients interacted the atmosphere was more relaxed and the mood seemed to lighten. Many of the patients in the noisy room were dozing off — it's peaceful for a while! This period before lunch, a low activity time, provided those staff members, who were so inclined, with an opportunity to engage with patients in a more informal, unstructured and personal way.

At 11.50 a.m. patients were assisted to the dining room for lunch which began at 12.15 p. m. and again the level of activity and noise increased significantly as carers began the task of serving meals and feeding patients. As dinner lids were removed from plates some carers grimaced at the sight of the food, and comments such as, 'I wouldn't eat that in a fit' or 'I wouldn't like to feed that to my grandmother' could be heard. At first glance it was impossible to distinguish between the semolina dish and the liquidised fish dish.

The carers distributed the meals. No patient was given a choice of food. Meal sizes seemed quite adequate but only the fast eaters managed to finish eating on time. A small number of patients were encouraged and prompted to self-feed, but, given that this process was slow and messy, some gave up, pushing the food away and indicating a lack of interest. Carers tended to hurry the slow eaters to finish meals as quickly as possible. Patients who required feeding were assisted by carers. Their main aim appeared to be to transfer the food from the plate to the patient's mouth as quickly as possible. No time was taken to inform the patient of what they were eating. As at breakfast, dirty dishes were collected and piled back on the trolley, patients were moved back to the sitting rooms for an afternoon sleep. Some had family visitors. The floor in the dining room required mopping as a consequence of the messy eating habits of patients. Once again the level of noise and activity dropped off and staff members retired to the staff-room for a lunch break — a somewhat unappealing environment in which to enjoy lunch.

6.3.2 Afternoon Shift

There was an overlap of staff between 1.30-3.00 pm. During this time a handover was given, some staff members had lunch/coffee breaks and patients had an

afternoon nap. The afternoon shift, which began at 1.30 pm, had a staff of one trained nurse and three nurse assistants, only one of whom was a regular staff member on the ward. The routines and activities with regard to care practices including the management of mealtimes and toileting rounds were repeated during the afternoon shift.

As the charge nurse undertook another medication round, it was clear that she found it difficult to concentrate on what she was doing while patients constantly called out to her for help or attention. Intent on remaining focused on the task at hand the nurse largely ignored the surrounding atmosphere of loud discordant and confused noises, as she moved methodically from patient to patient, administering medication. During the mid-afternoon, patients were more awake and some of the friendships and bonds with carers became evident over afternoon tea. It was noticeable that the patients did not seem to interact with each other, save to express frustration or anger at annoying behaviour. As the afternoon waned, some patients became restless and agitated due to the effects of their medication wearing off, or to the discomfort of incontinence. Following another coffee break, staff engaged in a burst of activity in response to patients' needs and in preparation for supper. Once again the familiar sound of the food trolley signalled the repetition of the mealtime routine and its associated tasks.

The carers had a supper break while dealing with interruptions from a few disgruntled wandering patients. All other patients were left to themselves for a while. Some dozed off to sleep, others fidgeted with pieces of clothing or rocked backward and forward in their chairs. At approximately 7.45 pm, preparations for returning patients to the sleeping area began and once again the migration took place. This was a fairly slow process since the transfer of each patient required the assistance of at least one carer.

Beds were turned down, curtains drawn, and patients assisted in replacing day clothes with night attire. One of the most important tasks at this time was ensuring that all patients were wearing pads to guard against wet or soiled beds during the night. Staff members attended to last-minute details, to ensure that patients were comfortable and beds were tidy and in order for the night shift. Some carers had another short coffee break and then a final check on patients before preparing to go home. The charge nurse began the task of writing up the required detailed notes and instructions for the injured patient who was to be transferred to another hospital for surgery.

6.3.3 Night Shift

At 9.00 pm, the night shift team — consisting of 3 enrolled nurses — arrived on duty. Only the charge nurse stayed from the afternoon shift to give the handover, which mainly focussed on the injured patient with only brief reference to other patients. The next part of the routine involved a medication round, drinks if needed, and settling the patients down for the night. The night staff checked patients every half-hour to ensure that nobody was trying to get out of bed unaided, and to ensure also that no one had soiled themselves. This routine continued until 7.00 am, when day staff members began the process all over again.

NOTE: This profile of a day in the life of the ward was typical of the daily routine observed throughout the duration of data collection for this project. Activities and routines seemed to follow a similar pattern from day to day.

6.4 The organisation of ward life and patient care

Many of the ward's routines, care practices, staffing patterns and other aspects of ward life seemed to follow the model of an acute care hospital. As outlined above, the day was divided into three shifts with the greatest number of staff (5) on the morning shift and fewer carers (4 and 3 respectively) on the afternoon and night shifts. The team leader on each of the day shifts was a senior member of staff and a qualified nurse, while an experienced enrolled nurse was in charge on the night shift. As in an acute care setting, this pattern of staffing tended to suggest that the orientation towards patient care was primarily task-focused — the higher numbers of staff being required in the morning and early afternoon when the bulk of work activity occurred. At the time of the project visits to the ward, all qualified staff were state-registered nurses, while nurse assistants were mainly without formal qualifications and had been selected primarily on the basis of motivation and flexibility. A small number of enrolled nurses made up the full complement of staff.

Following many visits to Karibu Ward at different times of the day and into the night over the first few weeks of data gathering, it became evident that several categories of activity could be readily identified from the profile of a typical day on the ward. For example, there was the routine *servicing* of patients such as, getting them up, dressed, fed, washed and toileted. Then there were *maintenance* type tasks such as, cleaning and tidying the ward, preparing snacks and hot drinks for patients, and making beds. There were also *nursing-type activities* such as, dispensing medication, taking temperatures and dressing

patient wounds. In addition there was *planning for special events* or occasions such as, the St Andrew's Day or Christmas parties, which formed another category in terms of time commitment. Finally, there were *low activity times* when carers took breaks for meals or to converse with one another.

Some variations in activity would be expected to occur from day to day depending on the individual carer. For example, the team leader had to attend to report writing and other clerical tasks. Some team members might choose to spend some time talking to patients, while others only seemed to do so when feeding, bathing or dressing the patients. However, as already indicated, the routine on Karibu Ward remained more or less the same from day to day.

In terms of how carers allocated their time, it became evident that most time was spent getting patients up, washed, toileted, fed and back to bed. A substantial but lesser amount of time was dedicated to tasks such as bed-making and other domestic-type duties — aside from the time spent several times a day on the medication round. Only a small proportion of time was required for nursing activities such as taking blood pressure or dressing wounds, relative to the time spent on coffee/meal breaks and social engagement among staff.

6.5 Themes Underpinning Care Delivery

Following several weeks of interacting with carers and observing them at work, it became evident that nursing practice on Karibu Ward consisted of daily and weekly schedules, which formed the backbone of patient care.

During the early weeks of making observations, it became obvious that carers adhered to prescribed methods of practice, underpinned by a commitment to set routines and approaches to care based on their assumptions about patients' needs. There was evidence to suggest that carers found it stressful and disruptive when regularised approaches to care or daily schedules were changed for whatever reason. It also became apparent that underpinning the delivery of care was a consistent emphasis on and commitment to the physical care of patients, even though carers varied in their perceptions of what constituted priorities in patient care. It became evident that inherent in those perceptions and other aspects of ward schedules, practices and carer experiences of working on the ward were 'points of tension' with conflicting perspectives emerging. These appeared to have significant bearing on patient care, carers' job satisfaction and the ward atmosphere. Based on these and

further observations the following themes emerged. A brief discussion on them will indicate why they are pertinent to the aims of this study.

6.6 Routinisation of Care

In the past, nursing was based primarily on prescribed methods of practice, the details of which could be found in any procedure book and policy statements strategically placed on wards. This resulted in standardised routines and approaches to patient care, with which the patient was expected to comply (Pearson, Vaughan & Fitzgerald 1997, p. 27). For some time however, it has become commonplace to criticise this approach as dehumanising, based on the argument that the patient is expected to comply with rules and regulations of practice without question or complaint, thus negating patient autonomy. This approach has been considered potentially more damaging to patients who, for example, are old, confused or who are, for whatever reason, unable to articulate their needs or wishes.

As already indicated earlier in the description of the daily rhythm of ward life one of the striking features of care delivery on Karibu ward is the extent to which it is routinised. It therefore seemed important to direct some attention to current literature that supports routine and order as critical elements of care delivery.

However, it is critically important to clarify what is meant by 'routine' in the context of dementia care, and, above all, that it does not mean overriding patients' wishes or ignoring their preferences. While advocating predictability and order for patients, Norman stresses the importance of realising that dementia sufferers may find it difficult to express their wishes and as a result 'are particularly at risk if care routines become inflexible and fail to respond to individual needs and preferences' (Norman 1999, p. 556). It is for these reasons then, that it seems important to reflect on how routines impact on the delivery of care on Karibu ward, given in particular the dependency levels of the patients. Those and other aspects of routine will be explored in Chapter 7.

6.7 Prioritising Physical Care

Carers' preoccupation with physical care appeared to be closely connected to the issue of routine. The physical care of patients was clearly a high priority for all carers. It was evident at all times that considerable value was placed on the visible aspects of care such as

cleanliness and running a tidy ward. Commitment to good physical care has its roots in traditional nursing practice, and its importance in dementia care has received considerable attention in recent times (Packer 2000; Chapman & Kerr 1995). It is also well established in the literature that people with dementia have special needs and caring for them requires knowledge and skills of a very practical nature. For example, it is strongly recommended that carers understand the importance of communicating effectively with patients, be competent and reassuring even when undertaking the simplest of practical care tasks and in particular when involved in intimate caring duties of a potentially embarrassing nature (Jenkins 1998; Jenkins 1999).

In a more general sense, getting through the workload seemed to be a main objective for each team on each shift. This aim or orientation is not new in nursing practice (Pearson, Vaughan & Fitzgerald 1998, p. 28). Completing practical tasks before handing on to the next team seems to be highly valued, and failure to do so could be viewed as 'individuals not pulling their weight', (unless there are some good reasons for falling behind with the work). This approach seems to set priorities in terms of care delivery and reinforces certain assumptions about what constitutes good care.

Attention will be directed to the way in which certain practical tasks were carried out and the degree to which it was evident that carers were consistent in attempting to engage patients in an encouraging and reassuring manner. Particular attention will be directed to how nurse assistants, who make up 74% of the staff, approached care tasks, given that they hold firmly to the view that only basic nursing skills of a very practical nature are required to undertake the majority of tasks defining patient care. In the same way discussion will focus on how perceived time-constraints influenced the way in which care tasks were undertaken and accomplished. The many prevailing influences on care delivery will be discussed in Chapter 8.

6.8 Communication Issues

Like many older people requiring nursing care the patients on Karibu Ward have difficulties communicating. As indicated in the literature, when an older person is no longer able to produce sequences of related ideas; when sentences are fragmented and they appear to be unaware of their surroundings due to the effects of dementia (Shamy 1993), communicating with others can be profoundly affected. The importance of developing ways of interacting positively with people with dementia is considered central to the task of care

delivery (Jacques & Jackson 2000; Holden & Woods 1995), and the practical aspect of communication continues to receive considerable attention from writers and trainers in the field.

The challenges of effective communication between carers and patients were consistently evident and multifaceted. Consideration will therefore be given to several factors such as 'lack of time' to explain procedures appeared to impact on care delivery. In the same way examples of effective communication and the use of humour and friendship to sustain patient-carer relationships formed critical elements of care.

During the data collection phase, a number of patients died on the ward and a number were bed-bound for long periods of time. As indicated earlier the physical care of patients and attention to their safety and comfort was always a priority. However, it seems important to reflect on how the social, emotional and spiritual needs of patient care were considered and managed and especially the needs of dying patients. Based on many examples these and other aspects of communication will be discussed in Chapter 9.

6.9 Environmental Influences

While there is no doubt that staff can provide good care for patients irrespective of the physical environment in which care is delivered, it must not be overlooked that poor design can make the task much more difficult (Cox, Gilhooly & McLennon 1997). While reference has already been made in Chapter 5 to the layout of Karibu Ward some further consideration will be given in Chapter 7 to the implications of ward design for patient care. Attention will also be given to the fact that carers made frequent reference to their own need for better facilities, and to the obvious absence of any discussion on the potential influence of environmental factors on what constituted adequate patient care.

6.10 Managing Challenging Behaviour

As discussed in Chapter 3 the management of patients whose behaviour is disruptive or abusive can be both challenging and stressful for carers. Shortages of staff, inadequate resources (Molony, Waszynski & Lyder 1999; p. 539), and lack of skill/training (Norman & Redfern 1997, p. 489) have been identified as some of the factors contributing to the stress

experienced by carers working on wards for physically and mentally frail elderly people who are abusive.

How a carer responds in a given situation may depend on a number of factors such as their skills and ability to reason with the patient in an attempt to lessen the risk; their willingness to recognise patient autonomy; their attitude/understanding of compulsory powers and the availability of help (Jacques & Jackson 2000, p. 279). One of the most significant issues arising from observations on Karibu Ward was the care and management of patients with disturbed or problem behaviour. It has already been stated earlier that the majority of staff providing care were care assistants who had only minimal training and/or education.

A case study will be used and other noted interactions between patients and carers will be drawn upon, to explore the potential and actual problems associated with managing abusive patients. The complexities of balancing patient autonomy with acceptable risk-taking and the importance of adequate and appropriate ongoing staff training, development and support will be explored in Chapter 9.

6.11 Conclusion

In this Chapter the following five major themes—routinisation of care, prioritising physical care, communication issues, environmental influences and managing challenging behaviour—have been identified and introduced as a basis for analysis of the data that reflect the nature of care delivery on Karibu Ward. These themes have emerged from observations of the rhythm of life on the ward, a sample of which has been presented at the beginning of this Chapter.

The issues identified tend to be rather specific, but other broad themes will also be analysed that will lead to discussion of ethical concerns and the implications for delivery of care. The issues in point are considered broad themes because from them other factors emerge such as the degree to which carers' needs are recognised and addressed; the implications of staff selection, orientation and ongoing training, and similar issues. Themes will be discussed independently, but connections will also be made between them due to the need to address the impact of some recurring critical elements such as carer training, professional isolation and perceptions of time constraints or care delivery. The aim in discussing the themes identified is to show how good care and quality of life for people with

dementia is underpinned by personal integrity and ethical choices that protect the dignity, privacy and freedom of individuals.

Finally, the data presentation and analysis in this study will conclude with an exploration in Chapter 10 of carers attitudes and feelings toward their role. This discussion will include issues associated with job satisfaction and perceptions that impact on care delivery.

CHAPTER 7:

The Impact of Routine & Environmental Influences on Care Delivery

7.1 Introduction

The themes to be analysed in this and following chapters are not selected in order of priority. It must also be stated that as the discussion continues, the links and interconnectedness of themes as aspects of patient care, will become evident. For example, carers seem to spend little quality time relating to patients, which may be because they do not feel skilled at communicating with them, combined with a tendency to give priority to physical care. In addition, the ward layout is designed for communal living and group supervision, rather than one-to-one interactions. The elements of this example, which will be explored more fully in the discussion of themes, tend to suggest that the way in which carers do things and interact with patients, may be influenced by a number of interrelated factors at any given time.

While no individual theme to be developed is more important than another, I have decided to start with discussion of *routine* followed by further exploration of *environmental influences* in the second half of this chapter. The rationale for beginning with *routine* was influenced by observations of its all-pervasive impact on how the ward was managed, how carers prioritised work and ultimately on how and what type of care was delivered to patients on a daily basis. It was also chosen because it is an aspect of ward life that is intended to facilitate the delivery of patient care but over which staff appear to have little control.

Attention will be directed to the routinisation of care on the ward and its implications for patients, carers and ward management. This will be followed by discussion of how it was evident and what seemed to be its influence and meaning, as an aspect of care on Karibu Ward. In the first half of this Chapter discussion will focus on the following:

- specific aspects of the morning schedules and their implications for patient care
- current practices and emerging issues in care delivery the purpose of understanding the implications for carers, patients and ward management
- alternative approaches to the management of similar schedules in other care settings for the purpose of illuminating the discussion
- the way in which and the variety of reasons why carers on Karibu Ward seemed to routine

- how the routine nature of the work is experienced by some carers as boring and depressing, while the repetitive pattern of tasks seemed to be a coping mechanism for others
- *routine* as a mechanism for managing difficult situations and sometimes
 - ✓ disgruntled, ungrateful patients, for the purpose of bringing to light what is realistically achievable and professionally acceptable in the delivery of care
- examples of nursing care which seemed to indicate that rigid adherence to routine practices was at times an impediment to meeting the needs of individual patients while, at other times, ensured that essential needs of all patients were met, especially when carers were under pressure for whatever reason
- how familiarity of *routine* seemed to help people cope in difficult situations, especially when staff relations seemed strained
- the sense in which *routine* consistently seemed a mixed blessing
- carers' attitudes toward the provision of non-routine aspects of care, providing some insight into how carers defined and prioritised aspects of patient care
- the various aspects of *routine* for the purpose of establishing, exploring and summarising the ethical and contextual issues inherent in current care practices and the implications for carers, patients and ward management.

7.2 Most People are 'Creatures of Habit'

There would appear to be considerable evidence to suggest that most people are creatures of habit or have habit patterns, that go with them wherever they travel, no matter what other changes occur in their lives (Toffler 1971). For example, a brief reflection on our own daily activities tends to indicate that we get up each morning at more or less the same time, catch the same bus or train to and from work each day, watch the same television programmes from week to week and so on. These are examples of decisions we take by habit and had we to make them afresh every day, which would be energy consuming and somewhat stressful. 'Take them (decisions) by routine or habit and that energy is conserved for more useful things'... 'a creature of habit is often a creature of wisdom' (Handy 1981, pp. 371-372). In much the same way, most behaviour of groups and organisations is governed by 'preset routines that provide guidance to individuals confronted by recurring demands' (Scott 1995, p. 22).

Activities are *routinised* to the degree that choices are simplified by the development of standard responses to defined stimuli (Genshy & Miller 1970, p. 96). *Routine* in effect means that employees become used to performing a task in a particular way, which potentially reduces the organisational difficulties of the group (Klein 1969, p. 69), conserves energy and creates a 'stability zone' (Handy 1981, pp. 370-371). Many early institutionalists viewed routines, that is, repetitive patterns of activity as the central ingredient accounting for the reliability of organisational behaviour and reliable performance, as well as for their rigidities (Scott 1995, pp. 54-55). According to Klein, 'the better a routine has been learned, the more reward its rigid keeping has brought in the past, the less willing will members be to abandon it' (Klein 1969, p. 69) when changes are introduced, bringing uncertainty and stress.

In general, routines can give a sense of security and order, conveying a sense of predictability and a feeling that things are 'under control' from a management perspective. On Karibu Ward certain care tasks are routinised while other activities fall outside routines and are therefore viewed differently. The profile of ward life outlined in chapter 6 provides an insight into the activities of a typical day. Ward management and patient care are underpinned by staff adherence to the various daily and weekly schedules that define and ensure the delivery of care. Attention will now focus on the rationale for some of the routines, their implications for carers, ward management and patients and an exploration of some of the issues that arise.

7.3 Ward Routines: The Morning Schedule

The overall aim of the morning schedule is to get patients up, washed, toileted, dressed and into the dining room for breakfast by 9a.m. Based on observations over a period of four months, this process was typically achieved by carers working methodically through a series of familiar steps. For carers, the smooth running of this schedule ensured that all patients were ready for breakfast at the specified time, but, the process was frequently disrupted for a variety reasons.

For example on several occasions during early morning observations it was evident that only some patients were awake and alert at 7 a.m. Carers had to wake others and this was often met with resistance. Due to incontinence, many patients had disrupted sleep and were often awake several times during the night, with a tendency therefore to sleep later in the morning. There were also approximately five patients who were typically 'night owls', preferring to retire later than the prescribed bedtime and to rise later in the morning. Meeting

the needs of these patients by accommodating their sleeping patterns was perceived by carers as inherently problematic in the management of the morning schedules and associated time lines.

This is in stark contrast to policies and practices elsewhere, for example in the nursing homes visited during the selection process for this study, as explained in Chapter 4. It is now common practice in many care settings catering for the needs of patients with dementia, that they be allowed to wake up naturally and are often given the option of a cup of tea before being washed and toileted. Breakfast schedules are flexible, usually spanning a period of approximately two hours. During this time, patients can go to the dining room in dressing gown and slippers to have breakfast and, if they wish, they can return to their bed for a period of rest. In contrast to this, carers on Karibu Ward start serving breakfast soon after 9a.m, and are usually finished by 9.40 - 9.45a.m. Given that one staff member dispenses medication at this time, this in effect means that four people serve the 20 patients breakfast in approximately forty minutes. This is particularly significant given that the three bed-ridden patients each had major difficulties swallowing food and all patients had a tendency to cough or choke if hurried while eating.

Carers did on three occasions in particular recognise the inappropriateness of the tendency to rush patients with their meals, not least because of the danger of a patient choking. On one particular occasion a carer reflected her unease, stating that she *'would not like to treat a family member in the same way', 'nor see a relative treated in that way by others'* — a 'yardstick' often used by staff members to express their dissatisfaction about aspects of patient care. This was an example of the impact of carers' perceptions of time constraints, articulated by one carer as follows: *'while it would be good to give patients a bit more time with their food, the truth is we don't have all day...'*. What in effect this carer meant was that the current approach to serving patients' meals was not appropriate, but it was the most time-efficient and facilitated the effective management of other ward schedules.

If the practices of other care settings were adopted on Karibu Ward, it would mean the process of getting patients up, dressed, washed and fed would take much more time. The usual chores of making beds and tidying the ward could not be neatly slotted into a specific time frame, as is the current practice. So what does the approach to patient management on Karibu Ward indicate? Why are those practices maintained and what are their implications?

7.4 Rationale Underpinning Ward Schedules

The rationale for getting patients through this early morning schedule appears to have its roots, as suggested in Chapter 6, in well-established traditional nursing practices on acute care hospital wards. In those settings patients have to be prepared for example, for surgery and doctors' ward rounds, which require that certain preparatory steps and procedures are completed earlier in the day. On Karibu Ward the same time schedules seem to be maintained for example regarding handovers and getting patients ready for the day ahead. These patients have very different needs; they do not have to be anywhere at any particular time and, as observed, they appear to spend most of each day sitting or just waiting for the regularised interruptions of meals and toileting activities. This approach in effect means that patients do not have a choice about when to get out of bed in the morning, get dressed or have breakfast.

Because meals are provided from the hospital kitchen, carers have no choice but to synchronise ward activities with kitchen schedules. As team leaders, nurses have been trained according to traditional nursing practices and seem to accept this approach as standard management practice for patient meals. Nurse assistants tend to follow the lead of trained nurses in this regard. In addition to the impact of management structures and staff training, these practices were perpetuated due to an absence of newer understandings of how dementia affects patients and the importance of finding creative ways for patient self-empowerment. From observations then, it became evident that the routines under discussion reflected a methodical approach on the part of carers, for the primary purpose of maintaining a proper order of things on the ward, the critical point being when and how these services were delivered.

The patients' subjective experiences, that is, their feelings, preferences and life-time habits with regard to their waking, sleeping and personal care routines were largely ignored or at least considered of little consequence within the context of current approaches to care. This confirms Chester and Bender's (1999, p. 68) view, as discussed in Chapter 2 that the internal world of the patient seemed to be of little or no relevance to the process of care. It also tended to indicate that the person with dementia is treated in this context as a non-person, because the option for decision-making is removed from the patient and the carer takes responsibility and control of the care process. This, by default, implies that the carer's role is simplified to that of taking responsibility for or control over the person with dementia, thereby raising a critical ethical issue regarding respect for patient autonomy.

Ethical practice demands that the principle of autonomy be upheld wherever possible, in particular, respecting the decision-making capacity of the person (Beauchamp & Childress 1994, p. 259). Since patients were not given choices about any aspects of the ward schedules, it can be concluded that, whether by design or default, carers were not in the habit of encouraging patients to make personal choices or engage in decision-making. To do this would have taken time which the schedule, as outlined and observed, did not allow. Besides, carers assumed that they should *do everything for* the patients, as will be established more fully in Chapter 8, when the emphasis on physical care is discussed. It can therefore be concluded that carers, in adhering to rigid ward schedules, were in fact not respectful of patients' potential to make personal decisions or of their possible willingness to be consulted on care matters.

At best it would appear that carers were unaware of patients' ability to engage in decision-making, or at worst that they chose not to engage with patients in this way due to perceived time constraints. It is being suggested here that both factors shape and maintain current practices. Carers seemed unaware of the capabilities of individual patients with regard to personal preferences, or at least assumed that patients did not have potential for decision-making. This claim will be substantiated in Chapter 9 when discussion will focus on the emphasis on physical care and the skills needed to communicate effectively with patients.

The way in which work is organised on the ward seems to facilitate 'getting the job done' with the maximum economy of human resources and within a specified time frame. This approach, which has been described by Wilson-Barnett (1983, pp. 110-111) in Chapter 3 as the *routine geriatric style*, is driven more by the needs of ward management and carers' preferred methods of practice than by patients' needs, as discussed above. A somewhat inflexible task-oriented approach appears to permeate the ward environment. If maximising the patients' personal control, that is, allowing them to continue being in control of as much of their life as possible, was a core element of care, then adopting a more flexible schedule would be necessary.

However, as already discussed, this could be difficult to manage in practice — with patients waking up at different times with little or no awareness, or sense of urgency — which might cause breakfast to extend over a period of a couple of hours. This in turn would impact on when other tasks such as bathing and bed making were undertaken and completed. Overcoming these difficulties in the interests of patient care would mean commitment to a more personalised approach to care and ensure that patients' needs, rather than management or carers' needs, were the primary motivating factors of care practices. It would appear that

carers need to find more creative ways of firstly respecting patient autonomy by engaging them as much as possible in decisions that affect daily living and ensuring that the tasks and goals that define good nursing practices are achieved by giving priority to patient needs.

The current morning schedule pressurises carers to complete specified care tasks by a certain time, and patients are expected to co-operate with the process. In practical terms this means that carers are very busy with patients from early morning until after breakfast, which is followed by a period of relatively low activity, as indicated in the typical day scenario in Chapter 6. This would suggest that the morning schedule of getting patients up, dressed and fed could be undertaken in a more leisurely way, reducing the pressure on carers and providing patients with more time and potentially more autonomy and choice, regarding the morning routine.

The delivery of breakfast from the hospital kitchen seemed to force the ward to fit a hospital-wide mealtime schedule, which does not appear to accommodate the needs of carers or patients. This situation could be easily remedied, as in other care settings, by having breakfast, which usually consists of porridge and marmalade sandwiches, prepared on the ward. This would not necessarily require the services of extra staff, since a more flexible approach to the morning activities would mean that not all patients would require attention at the same time, freeing carers to attend to breakfast preparations. In summary:

- Discussion so far tends to suggest that certain ward routines do not necessarily give priority to the needs of patients and tend to impose pressure on carers to complete prescribed tasks within a set period of time.
- It is also being concluded that the adoption of a more flexible schedule modelled on well-established practices in other care settings, would ensure the delivery of more effective patient care without additional costs being incurred.

However, carers seem to adhere to routines for a variety of reasons. Attention will now be directed to discussion of the way carers seem to rely on routine to get them through difficult situations and the monotony of working with apparently 'unresponsive' patients.

7.5 Routine: A Coping Mechanism

Following six weeks of observing work patterns and absorbing the atmosphere and activities of ward life, informal interviews were conducted during which carers were asked to express how they felt about working on the ward. These interviews were prompted *firstly* by the fact that the delivery of care seemed to be heavily influenced by the traditional

nursing model and, *secondly*, by the fact that there appeared to be no structured mechanism in place through which carers could debrief when feeling emotionally upset, pressured or anxious as a result of work-related demands. Thirdly, there was a culture of most carers taking regular breaks to smoke and have coffee, which seemed to be viewed as a survival mechanism.

When asked about their experience of working on the ward and how they felt about caring for patients whose condition did not improve, carers' responses fell into two somewhat distinct groups - those of nurses and nurse-assistants. Five of the ten nurse assistants indicated that they generally found the work to be *'trying at times'*, *'quite mundane'* and *'monotonous'*. The trying nature of the work they defined in terms of being faced every morning *'with the stench from wet beds and soiled bedding, enemas and the protestations of patients not wishing to be disturbed'*. Four nurse assistants said there were days when they felt depressed because of the unappealing nature of the work and the fact that the condition of patients deteriorated over time until they eventually died on the ward. In particular six nurse assistants indicated a lack of job satisfaction, while only one stated *'I often feel pleased at the end of the day, knowing that I have done a good job caring for these patients in their last days.'*

Nurses on the other hand were much less forthcoming regarding their feelings and tended to couch their responses in more matter of fact language. The sentiments of one nurse who said: *'working on the ward doesn't really bother me one way or the other'*, closely reflected the attitudes of four of the six nurses on the ward. When explored further, this perspective tended to reflect an emotionally detached approach. For example, two nurses said *'you just do what you can for them (the patients)'*, while another stated that it is simply *'a question of doing things to the best of your ability and doing the best for patient care'*. Another nurse said, *'you have to remember the good life they (the patients) had before'*. These responses tended to betray a rather passive attitude, based on the belief that little could be done for the patients, other than keeping them comfortable.

'Keeping patients comfortable' is a recognised care element and priority in nursing care and in particular for elderly patients, who are terminally ill and/or in the advanced stages of dementia. However, the development of gerontological nursing over the past two decades, including the recognition of distinct elements of nursing with older people, demands expert practice of nurses tailored to the specific needs of older people. While nursing these people is now an area of speciality, the practices on Karibu Ward do not seem to support the bold claim made by Heath and Schofield regarding the progress in gerontological nursing. Contrary to the authors' claim, it would seem there is some evidence

to suggest that challenges relating to ageist attitudes among nurses, poor or inadequate training, under-funding, second-class hospital accommodation, poor skill mix and a reluctance of nurses to work in this area, are still features of nursing care delivery (Heath & Schofield 1999, pp. 510-511).

Only one of the six nurses on Karibu Ward indicated – on numerous occasions – a real sense of dissatisfaction with the approach to and standard of nursing practice. She was eager to introduce activities for patients and believed that meeting their psychosocial needs was a critical aspect of care. She was also the only nurse who indicated that she was actually happy working on the ward in her capacity as trained nurse and team leader. None of the qualified nursing staff had training in this area of speciality, which according to the Royal College of Nursing requires that nurses develop highly specialised understanding and skills to meet the needs of older people, which are among the most complex encountered in any health care setting (Royal College of Nursing 1993, pp. 508, 516). For example, nurses need to understand the altered presentation of illness in older people. A chest infection may manifest in mental confusion, and the older a person is, the more likely they are to present with multiple disease processes. This can be complicated further by adverse effects of prescribed drugs (Heath & Schofield 1999, p. 511). It is for these reasons that adequate and appropriate training of nursing staff is crucial.

As noted by Molony, Waszynski and Lyder (1999, pp. 553-554), much depends on the knowledge and skills of nurses because the limited involvement of physicians in institutional geriatric care makes it unlikely that the patient and physician will have a doctor-patient relationship more typical of acute care or other fields of nursing practice. This was true on Karibu Ward, as indeed in most nursing homes. Older people, especially those with dementia are not only vulnerable to being left out of discussions on their treatment and care, but are also dependent upon the skills and knowledge of the nurse to make critical decisions regarding care — including when to call the doctor.

On Karibu Ward nurses adhered to familiar nursing care practices of giving priority to patient comfort and the provision of good physical care. As a group they seemed less emotionally influenced than nurse assistants by the unappealing aspects of the work, relying on familiar routines as a basis for care delivery. For example, when dispensing medication, which occurred four times each day, the nurse always remained focused on the task irrespective of the demands of patients or the many other distractions around her. Nurses are trained to observe set procedures when dispensing medication, such as never leaving the drug-trolley unattended. On Karibu Ward this particular activity was not only managed

according to professional practice, but was also an example of a very familiar and important nursing duty undertaken according to a set routine.

While nurses helped from time to time with toileting and feeding patients, they had other clearly identified responsibilities such as the drug-round and report writing, which physically removed them from some of the more unappealing aspects of patient care. Nurse assistants on the other hand were constantly in direct contact with patients and attending to their needs. For nurses then, the various nursing routines not only defined care but also gave validity and priority to what actually occurred by way of care delivery. Adhering to familiar nursing routines ensured the delivery of essential patient care, however trying the circumstances.

Nurse assistants on the other hand, also relied on routines but in a different way or for different reasons. For example, one nurse assistant said that having a *'routine is a good way of working and getting the tasks done for the day'*, while another said *'when you stick to routine you can see what you have achieved and that gives you a sense of satisfaction'*. On seven different occasions some of the more senior and experienced nurse assistants tended to express dismay when daily schedules were disrupted. For these carers adherence to routine practices was equated with a well-run and well-organised ward. Nurse assistants relied upon a routine approach as a method of ensuring that tasks were completed and from which they gained a sense of achievement and satisfaction despite the deteriorating condition of patients or the various other mundane and monotonous aspects of the work. For different reasons then, all carers seemed to rely on routine, as a coping mechanism in the delivery of care on the ward.

7.6 Resistance to Disruptive Routine Care Practices

Adherence to routine practices of care usually ensured that essential services were delivered to patients as a group, but this approach often lacked the flexibility to meet the needs of patients as individuals. For example, a few patients who tended to wander constantly would usually make their way back to their bedrooms during the day. However, on being noticed by staff, they were directed back to the day area for the purpose of easier supervision. The inflexible nature of observed routines and the rationale underpinning resistance to changing practice, is brought to light in the following scenario. In this incident a nurse assistant attempted to introduce a more flexible practice regarding patients' bedtime, but without success.

Mrs Kivlin had been on the ward approximately four weeks, during which time she seemed to have settled in well to her new environment. However, carers observed that Mrs Kivlin tended to become agitated toward the late afternoon and by early evening her whimpering noises often turned to piercing shrieks that could not be ignored. This occurrence was discussed at handover, when it was recognised that Mrs Kivlin did seem to know what was going on around her and was capable of raising an objection to staff if something was said or done that she did not like.

So what then was the message and/or meaning of her agitated behaviour each evening? One carer reminded the others present that prior to admission to the ward Mrs Kivlin was used to retiring to her bedroom and lying propped up on her bed for several hours before going to sleep. The carer went on to say that she had suggested to the charge nurse that Mrs Kivlin be allowed to continue this practice on the ward but the suggestion met with opposition. The charge nurse chose to manage the situation by instructing carers to remove Mrs Kivlin to the 'noisy' room when she became very agitated in the late evening. This approach was also strongly supported by the charge nurse present at the handover. The carer who recommended making concessions for Mrs Kivlin, made another attempt to explain that the patient in question would possibly become much less agitated, and by implication be less troublesome, if she were allowed to lie on her bed in the early evening and asked whether it would be possible to give this approach a try for a period of time. The charge nurse did not approve and closed the discussion by saying, 'we must not give in to her (Mrs Kivlin) by letting her go to bed at that time - it will only make trouble for night staff later'.

This scenario is an example of commitment to inflexible routines, as a result of which the needs of the individual are sacrificed to the needs of the group. This approach to managing the problem fails to respect the individuality and needs of the individual. It also implies that the patient was being manipulative and a nuisance. This approach to managing the patients' needs, infringes respect for the patient's autonomy by not giving her the choice of going to bed early. It also failed to treat the person as an adult, achieving an outcome in a manner somewhat more reflective of a parent-child relationship. Finally this approach gave priority to the routine ward practice over the needs of the person – keeping all patients in the sitting rooms for ease of supervision.

As already mentioned, carers favoured routine because completing prescribed tasks within specified time frames gave them a sense of satisfaction and achievement. Any digression from or interruption to the daily round of familiar tasks usually met with resistance from carers. This was particularly evident, for example, when social activities for patients had to be planned and managed and when bank or agency staff were employed to make up the full complement on a shift. Further exploration of these examples will bring to light the significance of routine in ward life and some of its positive and negative implications for care delivery.

Throughout the period of data collection, which included the Christmas season, several social events occurred on the ward. These required a substantial amount of planning time and the total support of all staff members, which meant a great deal more work for everybody. The focus here is on the issue of managing the process and the implications for carers, rather than on the appropriateness of the events for patients, which will be discussed in Chapter 9. For three weeks before the first social evening, which involved taking some patients out to see the Christmas lights in the city, one of the charge nurses had tried to co-opt other carers to help with preparations. She received very little support and her gentle cajoling often met with thinly veiled annoyance at the suggestion of more work. The charge nurse led by example on this and other similar occasions and, as a result, other carers gave their support in a somewhat grudging fashion.

Carers articulated what seem to be valid reservations about the effort involved in preparing social activities, without any extra help and they questioned whether it really made any difference to patients. The validity of these comments will be explored later, the critical point here being that carers felt putting on entertainment for patients was not part of the day-to-day life of the ward and they felt its demands on staff time and energy were difficult to justify. In other words these events were not seen as part of the routine, were not defined as essential to care and were primarily regarded as a serious disruption to the work and life of the ward, with questionable benefits. Routine practices then provided a clear sense of what was considered essential care and the undertaking of these practices served to provide a certain validity to the role of the carer — as distinct from how other tasks were perceived, such as planning and participating in social events.

7.7 Environmental Influences

Attention will now be directed to the second theme — the significance of the physical environment on the delivery of care. When asked what they thought was most important in terms of caring for patients on Karibu Ward, carers listed patient privacy; the availability of good-quality equipment; creating a homely environment; and ensuring patient safety and comfort among the list of priorities. Each of these features was influenced by and contributed in a significant way to the impact of the environment on the quality of patient care. It has already been established in Chapter 5 that the design or layout of the ward was quite traditional, with patients sharing sleeping quarters, as well as dining, washing and toileting

facilities. It was also stated that there were aspects of ward layout that seemed to militate against patient privacy and the provision of individualised care.

Picking up on points raised in Chapter 5 relating to the design of Karibu Ward and its facilities, this discussion will now focus on

- the relationship between environmental influences and care delivery
- issues arising from the relationship between shared spaces and patient behaviour and the implications of limited space on patients in particular
- the standard, use and availability of appropriate seating and mobility devices for patients and the implications of using outmoded equipment
- the quality of staff facilities and its implications for carers.

7.8 The Relationship between Shared Space and Patient Behaviour

One of the most obvious and persistent features of Karibu Ward was the noise level to which carers seemed to become desensitised. All of the patients were living with severe dementia, which was sometimes expressed in disruptive behaviours such as aggression, restlessness and verbal outbursts. The verbal outbursts often consisted of yelling, and calling out in a monotonous, whining voice that could not be ignored. Carers usually spoke quite loudly to patients when giving instructions, assuming the need to do so when patients engaged in null behaviour and did not indicate that they understood or heard the instructions. Instructions were often repeated over and over again, which could be quite aggravating to endure. Another main source of noise came from the use of trolleys, hoists, wheelchairs and other general ward equipment, much of which as already noted in Chapters 5 and 6 was fairly antiquated.

The aim of this discussion, however, is to draw attention to the fact that patients seemed to be negatively affected by noise, becoming more agitated and aggressive as noise increased or persisted as the following example showed.

All the 'noisy' patients, that is those who constantly demanded attention by shouting, or engaged in loud, aggressive or whining mutterings – were located in one sitting room, known as the 'noisy room'. The aim in locating the noisy patients in this room was to prevent them from disturbing other quieter patients or those who tended to sleep a lot. The understanding among carers was that the noisy patients tended to 'cancel each other out' in terms of creating noise, but the following incident indicates that patients in the noisy room did in fact annoy each other.

On one particular afternoon a patient who was relatively new to the ward was behaving in a very agitated manner. Her high-pitched voice was difficult to ignore and staff did not seem to know how to cater for her needs. Despite their best efforts to pacify her, the annoying behaviour intensified. Another patient who was supposedly asleep – and was usually very difficult to understand, whenever she attempted to communicate – reprimanded the first patient, telling her in no uncertain terms to 'shut up', her voice trailing off into muffled tones which clearly reflected her annoyance. This response surprised the two carers in the room. The ongoing interaction between the two became somewhat unpleasant, disturbing other patients in the room. Carers intervened by distracting both patients, diverting their attention away from each other and the tense atmosphere.

However, it is important to note that neither patient had the option of moving from the room to another space for relief. This is an example of how patients were forced to live communally, irrespective of how they felt, because the design of the ward did not provide alternative options for individuals to have a quiet space where they could be alone, should they so wish. The incident relates to a point made by Goldsmith (1996, p. 99) that carers need to acknowledge that patients, like the rest of us, have likes and dislikes and may object strongly to the behaviour of other patients, as in this case. This example also challenges the assumptions that it is satisfactory to locate all noisy patients in one room because they 'cancel each other out'. On this particular occasion, carers dissipated the patient's anger by distracting her – a temporary rather than a long-term solution to a problem that arose from forced communal living.

The interaction between the two patients, outlined above, suggests that they did in fact become quite agitated by each other and such situations can escalate, becoming unpleasant for other patients and difficult for carers to manage. When I asked the carers why they were surprised at the patient's response, one carer indicated that she had always assumed that the lady could not speak and was surprised to hear her reflect her annoyance so clearly. The other carer said 'I just always thought she was not bothered by what went on around her'. Those assumptions tended to suggest that carers' knowledge of and insight into the needs and preferences of the individual patients in question was somewhat lacking. This example also highlighted the fact that in general carers seemed to only have generalised rather than personalised knowledge of the patients in their care.

Forced communal living due to lack of space seemed to lead to conflicts such as the incident just discussed. The lack of space also became problematic on other occasions, such as the St Andrew's Day party, when relatives of patients attended in order to be with their hospitalised relatives. On each of these occasions patients became more agitated, resulting in some patients becoming disruptive and having to be removed, thereby creating greater

supervision problems for carers. These situations arose because the ward did not have a room large enough to cater for the needs of patients and visitors on such occasions.

However vigilant carers are, in guarding the privacy and dignity of patients, it is almost impossible to ensure high standards are upheld in circumstances where patients share sleeping, dining, washing and toileting facilities. The design of the ward and its routines were best suited to communal living, but appeared to neglect the needs of individuals for space, privacy and time to be alone or with relatives. Many of those points have already been established in Chapter 5 with regard to the problems associated, for example, with shared toilets and the way in which having a personal toilet and shower could help humanise the environment.

Many patients engaged in null behaviour - that is, staring or simply doing nothing – and did not seem to interact with each other. It would appear that communal living provided patients with no opportunity to choose between privacy and socialisation. Patients had little relief from each other or the routine of daily life on the ward. The implications of communal living and limited shared space had a flow-on effect for patients and their visitors. During family visits it was evident that visitors seemed a little awkward, trying to relate in a personal way to patients. These meetings usually took place in one of the sitting rooms, with many other patients present and staff constantly moving in and out of the room. The visitors' room was usually only used by those patients who could walk there with their relatives.

The majority of patients were confined to chairs in the sitting rooms, which meant they actually had less privacy than patients in acute hospital wards where visitors can sit on or by a patient's bed and pull the curtain around the bed to ensure some privacy. The visiting arrangement on the ward was particularly limiting for patient-relative interactions, given the limited and deteriorating capacities of patients to relate in meaningful ways, even in the most ideal circumstances. For example, one patient who had regular weekly visits from family members was chair-bound, spending her days as one of a group of 8-10 patients in one of the sitting rooms. Her visitors had no alternative but to try to communicate in a personal way with their mother in the midst of the usual noise and activity of the sitting room which seemed quite inappropriate. The design of the ward and more specifically the total absence of access to personal or private space created many difficulties. Of concern was the lack of sensitivity to patients' needs for privacy, and a lack of awareness of the impact of their environment on patients and visitors.

As already indicated, the day area of the ward has three sitting rooms, which accommodate patients throughout the day. Given the number of patients and the space required to mobilise them for toileting, bathing and meals, the rooms always appear fairly

crowded. While there is a family visiting room for relatives, there are no other spaces or areas to which patients can go. If for example a patient may simply want some 'space' from others or escape for a while from the bustle of the ward, there are no options available since the sleeping quarters are out of bounds during the day. This in effect means the patients have no choice but to put up with the irritations of communal living, as the following example indicates.

One of the sitting rooms is referred to as the 'noisy' room. All the noisy patients, that is, those who constantly demand attention by shouting, moaning or banging on objects, are located in this room. The aim of this arrangement is to prevent these patients disturbing the quieter ones who appear to sleep for many hours during the day. The rationale is that the noisy patients tend to cancel each other out, and that they are a source of irritation to other patients and staff rather than to each other.

There is, however, no other space available on the ward to which a patient can be removed from what may become a tense and irritating environment affecting all patients in the room. In support of this example, Goldsmith draws attention to the fact that carers need to remember that patients, like the rest of us, have likes and dislikes and there 'may be people with whom they get on very well and others to whom they take an intense dislike' (Goldsmith 1996, p. 99). Rader also draws attention to the fact that in many nursing homes where patients do not have a choice between privacy and socialisation, they often engage in null behaviour - 'a lack of any observable behaviour or activity ... 'doing nothing' and 'staring' (Rader & Tornquist 1995, p. 70). It is important therefore that carers acknowledge and understand feelings that come into play with patient interactions and where possible assist the patient to manage these in positive constructive ways.

Karibu Ward has a strong clinical atmosphere and is designed to cater for the physical care of patients, their communal living and communal activities. However, the structure of the environment and the regulations underpinning patient supervision and safety, force patients to be in each other's company, day in and day out, without relief. While the design of the ward facilitates the constant observation of patients and the effective provision of physical care, the design also seemed to influence negatively other aspects of patient care — e.g. the need for a calm environment, or private space for patients to be with relatives during visits.

7.9 Use and Availability of Appropriate Seating and Mobility Devices for Patients

Encouraging patients to be independent and promoting mobility are key features of current thinking on dementia care. As indicated earlier, the majority of patients on Karibu Ward were chair-bound. While a few patients could move around independently, in reality almost all patients spent their days seated and were transported to and from the toilet or bathroom by hoist or wheelchair. Equipment in the form of seating and mobility devices were essential to patient comfort and to how carers undertook certain tasks. However, the quality and use of equipment appeared to be problematic for both carers and patients, evidenced by the recurring complaints articulated by staff. When asked in interviews how they felt any potentially available resources should be spent on the ward, all carers, without exception, stressed the need for more adequate equipment for the patients' care, such as chairs that provided greater support and comfort and hoists that could be more easily manoeuvred.

Reference has already been made in Chapter 5 to the fact that there was a collection of chairs of different sizes and shapes available. Some of these chairs seemed reasonably comfortable but many patients frequently appeared restless when seated and tended to slump into uncomfortable positions, or slide off the chairs. There were however a small number (3 or 4) of chairs, which were easy to mobilise and comfortable for patients, but these were very expensive and only available to patients whose families provided them or, in one case, a chair was left for use on the ward by the family after the patient had died.

Carers complained about the problems associated with using antiquated hoists to manoeuvre patients in and out of chairs and baths. Reference has already been made to the cumbersome, unsteady and outdated models of hoists in current use. Also mentioned was the need for more user-friendly equipment for the benefit of carers and patients. There was further evidence to suggest that the poor quality of equipment extended beyond those items mentioned above. During the period of observations the fridge in the pantry for the use of patients and carers was condemned 'after months of complaining to those in authority' – according to one of the nurse managers - and reference was made to the fact that other items such as the toaster should also be condemned.

7.10 Staff Facilities

While carers were aware of the need to improve or upgrade equipment for use in patient care, they were more dissatisfied with the condition of staff amenities. Both nurses and nurse assistants felt some basic facilities such as a microwave oven were needed to make basic improvements to the staff room. These would require only moderate resources.

This had several consequences: Firstly, a few carers who did not smoke had objected to the unhealthy smoke-filled atmosphere in the staff room and as a result avoided spending time there with colleagues. This had a divisive effect on the staff and tended to carry over into aspects of work. Secondly, while no other space was available as a smoking room for staff on the ward, neither was it feasible to have carers leave the ward to go outside for a smoking break. By remaining on the ward, carers were more readily available, even when having meal breaks, to attend to patient needs if any difficulties arose. Thirdly, there was a no-smoking policy for patients, yet the staff room was fairly central to the ward. As a result it was difficult to tell what impact carers who smoked might be having on patients who had been smokers in the past. For example one patient was observed smoking during visits from relatives. Carers either decided to be lenient or turn a blind eye!

The inadequacy of basic equipment in the staff room suggested that the staff needs, as an aspect of ward life, were not given priority. In the same way, the extent to which carers found it necessary and acceptable to smoke in such a confined space was indicative of a need to relieve stress and/or the monotony of what many of them described as 'trying', 'mundane', 'unappealing' work. Mingling and conversing with carers in the staff room over four months revealed something of the level of cynicism and emotional exhaustion experienced by them. As discussed in previous chapters there was a high and consistent dependency on the services of bank and agency staff to maintain staffing levels on the ward. It was beyond the remit of this study to draw any conclusion from levels of staff stress and absenteeism or turnover of staff on the ward. Rather, what is being suggested is that the staff room could be described as a kind of barometer - a place that reflected how carers felt about themselves. Staff often seemed physically and emotionally exhausted, bored from work that did not change from day-to-day, and with little sense of personal achievement. The poorly-equipped staff room seemed to reflect the degree to which carers' needs were not considered and ultimately the degree to which carers were valued as people and respected as workers.

With regard to staff room facilities there was little evidence to support the philosophy of dementia care, which suggests an equal concern for the needs of staff and patients (Archibald 1997). What is required is an environment in which staff members can

spontaneously reflect their feelings. The feelings expressed by staff were for the most-part more indicative of the emotional exhaustion and tedium experienced rather than any enthusiasm born of creativity or a sense of accomplishment (Moniz-Cook & Silver 1997). The poor quality of the facilities for staff indicated first that carers' needs were not given priority, and secondly that carers did not seem to know how, nor did they have the energy, to manage their feelings of tedium and strain in healthy and constructive ways. If these observations are correct, one has to ask what the flow-on effect was for patients. How long would carers be able to give of themselves personally and professionally so as to ensure the delivery of high-quality care to patients?

7.11 Conclusion

This chapter began with the observation that routine seemed to have an all-pervasive impact on how care was delivered on Karibu Ward. The aim has been to explore the routinisation of care for the purpose of identifying issues arising and their implications for patients, carers and ward management. Based on day-to-day practice some activities and practices of an ethical nature have been identified and explored. For example, from reflecting on the morning schedule it became clear that carers undertook care activities in a very routinised manner with the aim of completing them within a set time frame. This approach was very methodical and tightly scheduled, based on the assumption that it was their role to do these tasks for the patients, rather than with them.

An alternative approach has been considered as a potentially more flexible method of care that could accommodate patients' needs as the recipients of care. It also became evident that elements of patient care were secondary to the needs of hospital or ward schedules. This was particularly related to and evident in the planning and delivery of meals to wards. Attention was drawn to carers' feelings of depression and dismay associated with working on the ward. Carers' commitment to routine and resistance to any disruption to routine care practices made it evident that the needs of individual patients were sometimes sacrificed to the needs of the ward or carers.

How design of the physical environment can affect care was also considered. Based on the belief that 'people with dementia have similar basic needs to other people of their age and that illness makes them more vulnerable to a badly functioning and poorly designed physical environment' (Annerstedt et al 1993) the implications of the poor quality of the ward facilities and design were considered. Difficulties and shortcomings were identified in terms

of their impact on patient needs. There was little evidence to suggest that carers were aware of how aspects of routine and/or the layout of the ward impacted on patient needs. It was established that priority did not appear to be given to carers' needs — as reflected in the inadequate staff facilities available. This had the effect of carers feeling 'taken for granted' and unvalued in the overall functioning of the organisation. This is entirely contrary to thinking, which stresses the importance of identifying and meeting carers' needs as a critical aspect of effective care delivery to patients. It is concluded that senior management need to appreciate that 'sensitive and effective support structures are essential' to avoid staff dissatisfaction and prevent high rates of staff turnover and sick leave. In other words, ongoing neglect of the needs of staff has the potential to diminish their capacity and wish to maintain delivery of high quality care to patients (Beth & Stokes 1999, p. 213).

The carers' commitment to physical care, through the routinisation of care in particular, emerged as an important theme. Understanding the significance of this emphasis on physical care will be the first theme discussed in the next chapter. It is expected that some issues will identify the possible need for palliative care for some patients.

CHAPTER 8:

Prioritising Patient Care

8.1 Introduction

This chapter is concerned with another element of care that is often closely associated with the routinisation of care that is, a preoccupation with and a *significant emphasis on physical care*. As already mentioned in Chapter 6 it was evident at all times on the ward that considerable value was placed on the visible aspects of care such as cleanliness, the physical comfort of patients and the running of a tidy ward. Getting through the workload was always a clear objective for each team on each shift. Failure to complete tasks before handing over to the next team was generally not well received. This particular approach seemed to set priorities in terms of care delivery and reflected and reinforced certain understandings and assumptions about patient needs, patient care and priorities with regard to what constituted good care on a day-to-day basis.

In this chapter the following issues will be examined:

- what carers identified to be priorities in patient care and how this was evident in the way carers chose to manage given situations
- examples of care delivery and the degree to which current approaches actually meet patient needs
- how specific practices and the ward culture with regard to staff training seems to reinforce and sustain unhelpful approaches to care
- the significance of the emphasis on physical care with a view towards establishing the prevailing influence of the medical model on care delivery
- the strict adherence to the repetitive task 'syndrome', coupled with an emphasis on a task-based work system designed to 'get the job done'
- nursing care that is primarily batch-provided rather than individually oriented in approach, with the implication that a 'warehousing' (Evers 1981) approach to care was adopted on the ward with adverse consequences for patients.

Before proceeding to explore the issues identified above, it seems important to briefly recap on the specific characteristics of the twenty patients on Karibu Ward and their dependency levels. The aim of the recap is to bring the recipients of care – the patients – into focus and by directing attention to the dependency levels of the patients, to provide a backdrop for the ongoing discussion of care delivery.

8.2 Specific Characteristics and Dependency Levels of Patients

All patients on Karibu Ward have been described as in the advanced stages of dementia. To varying degrees the patients were confused, dependent, non-conversant, mainly non-ambulant and incontinent. All patients required assistance with dressing, while approximately fifteen needed help in feeding and only three or four were ambulant. The majority of patients had major difficulties communicating their needs and feelings, while approximately three of them managed to make contact with others through fragmented conversation. As dementia progressed and verbal communication became increasingly impaired, the process of identifying patients' needs, such as diagnosing pain intensity or other patient discomfort became more difficult.

The majority of patients had difficulty recognising familiar people and their ability to interact socially was generally quite impaired. As a result, individual patients tended to become isolated, their cognitive impairment causing them to become withdrawn from social interactions and conversations with others, ultimately leading to patients becoming strangers to one another. Significantly reduced insight and sensory ability often coupled with impaired hearing and deteriorating eyesight, impeded patients from expressing their wishes or making carers aware of their needs. Cognitive impairment was often evident in behaviours such as forgetfulness, an inability to use their powers of reasoning, inability to focus attention, and a tendency to become disorientated.

Cognitive impairment was also evident in other ways, such as patients' engaging in repetitive questioning, which often seemed frustrating for carers as well as other patients. Behavioural changes and the deteriorating mental state of patients often proved challenging for carers. Endless wandering, verbal and physical aggression were fairly typical behaviours evident among at least half of the patients. The reasons for these behaviours were sometimes puzzling for staff, yet their purpose was not necessarily meaningless, as will become evident later. Signs of agitation, restlessness and disturbed sleep were common among patients. Again, what these symptoms indicated and their significance, required understanding on the part of carers, so that patient needs could be met. How well challenging behaviours were understood and how well carers managed to intervene in effective ways, seemed to vary considerably from carer to carer.

As already outlined in Chapter 4 nurse assistants made up almost 74% of the overall staff complement. They held firmly to the view that only basic nursing skills were required to undertake the tasks defining patient care. Basic nursing practice was defined in terms of keeping people clean, warm, fed, toileted and put to bed. While nurses also believed that

attention to these identified needs was at the core of what constitutes good patient care; they identified, for example, the availability of high quality staff members as essential to the delivery of adequate patient care. How carers perceived and what they felt about their respective roles as trained nurses and nurse assistants seemed to have had a significant bearing on how care was delivered and how the ward was managed. The implications of these issues will be discussed in Chapter 10.

Since the purpose of this chapter is to explore the emphasis on physical care, attention will focus on specific examples of patient care and on how nurse assistants and nurses chose to manage given situations. Attention will initially be directed to what carers considered to be priorities in meeting patient needs. Examples of care and the degree to which current approaches actually met patients' needs will be analysed in the light of our observations and relevant research.

8.3 Prioritising Patient Needs

It was generally the understanding of carers that patients on the ward were almost totally dependent on them for all aspects of care. This understanding seemed to be reinforced, at least in part, by the fact that many of the patients had progressed to Karibu Ward from other wards in the hospital complex that catered for more independent patients. During orientation to the ward the dependency levels of the patients were reflected by one carer in the following terms: *we have to do everything for the majority of these people, so it's a real bonus when we get a new patient who can more or less feed or toilet herself*. These sentiments, which were expressed repeatedly in later conversations by individual carers, reflected a perception of patients as child-like figures, dependent upon somebody who knows – in this case the doctor and/or nurse. Based on these assumptions and on some weeks of observations, carers were asked what they felt were most important issues in patient care in terms of priorities for care delivery.

All carers identified giving due attention to patient comfort, safety and the care of bodily-functions as the priorities. These responses were consistent with how carers seemed to allocate their time in the delivery of care, giving priority to the physical needs of patients and only then to other service tasks and domestic-type duties. What is of particular interest here is how carers ensured, through this process of prioritising care, that the needs of patients were met. How well carers seemed to respond to and understand patients' needs will now be considered more closely through the use of the following scenario: Caring for Mrs Clarke.

Mrs Clarke was relatively placid, with a tendency to spend a lot of her time on her own, withdrawing from interactions with other patients. She was not orientated to time or place but recognised staff and family members. Over a period of a few months Mrs Clarke's behaviour changed. She became increasingly more lost and confused. She would often be found weeping uncontrollably. She needed assistance with dressing herself, and took little interest in her appearance. She suffered from urinary and faecal incontinence and was on occasion uncooperative when staff undertook the toileting rounds. Mrs Clarke often showed little interest in her food, needing to be encouraged and reminded to finish her meal. She was given medication to help her sleep but sometimes refused to take it. This presented staff with practical difficulties in terms of knowing best how to deal with her.

Carers were at all times committed to ensuring that Mrs Clarke was clean, well groomed and toileted regularly, despite her many protestations. They also supervised her during mealtimes, sometimes feeding her when she appeared particularly absent-minded regarding her food. With regard to Mrs Clarke's behavioural changes and emotional state, carers seemed simply to accept the fact that she was withdrawn, preferring her own company. Her increasingly confused state was viewed as another sign of her progression into the more advanced stages of dementia. Carers would try to comfort Mrs Clarke – by making her a cup of tea and taking her for a little walk to distract her – whenever her crying became particularly stressful to herself and/or others. Carers did not seem to explore the cause of this behaviour because they felt it was simply their role to comfort her to the best of their ability, in the manner described and when time permitted. This was because they accepted her behaviour as typical of a person in the advanced stages of dementia. To explore Mrs Clarke's feelings with her would have taken some time, which carers seemed to feel was not available or would not meet with the approval of other staff — given the demands of other patients. The importance of understanding Mrs Clarke's feelings was not perceived to be a key to understanding what she was trying to communicate or how best to care for her.

As her weeping episodes became more intense and more frequent - the attempts to comfort her had little effect. A charge nurse arranged for a visit from a doctor and Mrs Clarke was given a thorough medical assessment. Medical advice indicated that there was no evidence of a physical illness such as chest or urinary infections, as the likely cause of the patient's distress. Medication was prescribed, which had the effect of keeping the patient calm and causing her to spend many hours sleeping each day. The prescription of medication had the effect of changing the nuisance or difficult behaviour of the patient to a much less stressful state for the staff. This was perceived by carers to be a positive outcome. In other words, the more peaceful the patient was, the less demanding and easier she was 'to manage'.

The 'management' of Mrs Clarke was fairly typical of the steps taken in the process of caring for patients who presented with similar problems. For example, there was a patient who had aggressive outbursts and tended to abuse staff and another patient. She constantly called out for help. Following assessment, she was prescribed medication as a result of which the presenting behaviour became 'more manageable'. This approach ensured that all possible physical health problems were assessed and that all patients were kept comfortable, safe and generally well cared for. What is worthy of note is the fact that assessment and treatment were referred to and decided by the doctor, as the ultimate source of knowledge. While the outcome of the medical intervention was the modification of patients' behaviour, the process did not help explain the meaning of the distressed behaviour of patients.

Carers were aware of patients expressing a range of feelings such as sadness, fear or anger, but the importance of those feelings, in terms of *what the patient was trying to communicate*, was generally not considered critical to the assessment process. The process of caring for patients was underpinned by a nursing approach that relied almost entirely on a medical diagnosis and solution to problems and for the direction of care. This tends to suggest that general nurse training played a significant part in the specific approach to patient care on the ward. In other words, nurses were primarily orientated to finding medical solutions to patients' problems.

While keeping patients comfortable was always a priority for carers, the importance of addressing their social, emotional and spiritual needs did not seem to be considered integral to this aim. This is not to suggest that these needs were never met, but rather to propose that when they were met, it was often dependent on the particular approach of individual carers or by default, in the course of practice, as will be established in Chapter 9.

8.4 Evidence of the Prevailing Influence of the Medical Model on the Management of Patient Care.

According to Kitwood's person-centred approach to care, care should be concerned primarily with the maintenance and enhancement of personhood. Providing a safe environment, meeting the basic needs and giving physical care are all essential, but only part of the care of the whole person (Kitwood 1997, p. 136). Kitwood expands on what care entails, based on the belief that the person may have obvious difficulties achieving even the simplest task, responding to the simplest question or asking for what they want, but the

person also has qualities and strengths, all of which warrant respect (Chapman & Kerr 1995, pp. 27-29).

There was little evidence to suggest that carers on the ward were particularly aware, or encouraging, of patients' remaining strengths and abilities, but there was abundant evidence to suggest that catering for the basic needs of patients, as outlined above, primarily defined care according to the carers' expectations. This was supported in practice by time management and the manner of prioritising care tasks on a daily basis.

On this evidence alone it can be concluded that carers – consciously or unconsciously – defined and prioritised care according to traditional nursing practice and the medical model. There were, however, several other indicators in the management of patient care that tended to reinforce the impact of the medical model on practice, with adverse consequences for patient care. For example, Mrs Clarke's weeping might have had several causes. However, carers chose to build on the evidence that her lack of orientation to time and place, coupled with her increasingly confused state, were symptomatic of 'the global impairment of higher cortical functions... (a condition that is) irreversible and progressive' (WHO 1986). This definition, recognised by WHO and the Royal College of Physicians, uses unambiguous medical language to define disturbance collectively referred to as dementia. The definition has its roots in a medical paradigm based on the belief that changes in the brain cause behavioural changes, resulting in a series of stages which become progressively worse.

While carers never referred to the condition of any patients in the specific medical terms outlined above, they did hold to the understanding that when any patient had, for example, difficulty retaining information, identifying time, places or people, or showed impaired judgement, it was because of the impact of the disease on the patient's brain. They also generally understood that the condition would deteriorate in every case and for this condition there is no cure. Carers consequently perceived emotional reactions, mood changes and challenging behaviours too as symptomatic of the deteriorating state of the patient's brain. This perspective is closely aligned to the medical view of dementia as a devastating disease of the central nervous system, in which personality and identity are progressively destroyed (Kitwood 1997, p. 136). Kitwood on the other hand perceives dementing illnesses as forms of disability, but believes that the degree to which a patient is affected depends crucially on the quality of care (Kitwood 1997, p. 136).

So when carers tried to comfort Mrs Clarke with a cup of tea, they were simply trying to be kind, but they appeared to lack the understanding and skills to explore the cause of her weeping or reasons for isolating herself. Carers seemed to rely upon the advice of medical practitioners, based primarily on drug administration, to manage such situations. There are

obvious ethical implications of adopting this particular approach to care, as there are specific practices that perpetuate dependency on the medical model, which warrant further exploration. Attention will initially focus on some of the dilemmas that arose in relation to current practices on the ward and their potential to significantly diminish the quality of patient care.

8.5 Some Ethical Consequences of Current Practices for Patients

A major problem with the generalised medical approach is the assumption that a disease follows more or less a similar path of development for each person, failing to recognise the differences in individuals. These may be due to the influence of their life experience, personality, coping skills, living situations, beliefs and values (Parker & Penhale 1998, p. 16). With regard to practice on Karibu Ward, there was little evidence to suggest that getting to know a patient's background, history or interests played any significant part in caring for the person, as the following observations will reveal.

Toward the end of a handover on a particular day, at the start of the afternoon shift, the charge nurse gathered together all carers in the staffroom to inform them of the arrival of a new patient to the ward later in the afternoon.

Charge Nurse: Mrs Kirk is the new patient who will occupy bed 2 in Room 3. She is being transferred from Seaview Homes due to her tendency to wander - Seaview has an open door policy and is no longer suitable accommodation for her.

Nurse Assistant: So apart from being a wanderer is she able to feed and dress herself?

Charge Nurse: Yes, I understand Mrs Kirk is not a problem patient, although she suffers from depression and can be withdrawn, but she has been described as generally co-operative and should be okay since this is a locked ward.

The charge nurse concluded her remarks by making reference to the fact that Mrs Kirk had a husband who was frail and only occasionally managed to visit his wife.

This scenario was fairly typical of the information carers in general received about patients, while it must be recognised that charge nurses would generally have added information about patient medication and any nursing or medical problems pertinent to the transfer of the patient. [Before proceeding any further, it is important to clarify the intent of the nurse assistants' query regarding Mrs Kirk's ability to feed and dress herself. This question indicated that they hoped that their resources would not be stretched any further by

the admission of another high maintenance patient, rather than a specific interest in identifying Mrs Kirk's coping skills, for the purpose of finding creative ways of ensuring that she continued to use them to the best of her capacity.]

Several other points need to be made regarding Mrs Kirk's admission to the ward. For example, attention was primarily focused on her behaviour as a wanderer rather than on her as a person. The problem behaviour was automatically located in the patient without consideration of possible difficulties associated with the environment of care or problems with individual carers. In other words there was no information available on how well carers at Seaview Homes attempted to meet Mrs Kirk's problem behaviour – wandering. Carers were given no positive message concerning what could actually be done for Mrs Kirk or what might she be attempting to communicate with her behaviour. For example, Mrs Kirk might be frightened or feeling isolated or lonely for some reason.

When Mrs Kirk arrived on the ward, staff were dismayed to find she was incontinent, verbally and physically abusive toward carers and generally uncooperative. Her wandering was the least of their problems with her. Staff felt duped and, as the days went by, it became evident that Mrs Kirk's behaviour could not be explained away as the teething problems associated with adjusting to a new home. There appeared to be some discrepancy between the information shared by the charge nurse regarding the patient's well-being, and carers' actual experience of the patient's behaviour. Even if more information had been available on Mrs Kirk, the time constraints on handovers did not permit the sharing of detailed information, however necessary it might be. The sharing of such information was obviously dependent upon what understanding the charge nurse had in the first place from the admission of the patient to the ward. Secondly, much depended upon what the charge nurse deemed important and necessary for other carers to know and understand as a basis of care. Thirdly, nurse assistants rarely participated in handovers or asked questions.

Another important point was the way in which patients were described and thought of by carers. For example, Mrs Kirk was described as a 'wanderer', others were known as 'wetters' or 'feeders'. The use of these descriptions indicated that patients were categorised according to the staff's task oriented conception of work. The descriptions tended to dictate the way in which staff interacted with patients and were the basis for patients' becoming depersonalised objects of the task-centred routines. This tendency to describe or relate to patients according to their condition has its roots in the medical model, which has long been criticised for its failure to be person-centred rather than disease or illness centred.

8.6 Further Ethical Implications of a Medical Based Approach to Care

In the past, it was assumed that the nurse or carer was in a position to speak for the patient and that the latter was unable to speak for herself. This was especially true of patients with dementia. However, more recent evidence suggests that neither of these assumptions are necessarily valid. Numerous frameworks have been created, for a variety of purposes, serving as guides to carers:

- to ensure the promotion of equity in provision and delivery of care
- for the purpose of self-monitoring staff training and development
- for the management of conflict.

While some frameworks can be mainly technical in nature and primarily focused on service provision and delivery, the current thrust in dementia care is to ensure that care practices are driven by frameworks that are predominantly person-centred, having the needs of the individuals as their primary frame of reference. With regard to practice on Karibu Ward, it would appear that carers' limited understanding of what constitutes the essential elements of care was heavily influenced by many of the limitations of the medical model. The quality of care offered could have been improved with better training and development opportunities for staff.

Reliance on the medical model has encouraged patient dependency, use of medication to manage patient behaviour and the depersonalising tendencies inherent in medicalised carer-patient relationships. Because some of the effects of neurological changes caused by the disease can now be managed more effectively with medication, this tends to reinforce practice based on the medical model. Chester and Bender (1999, p. 68) point out that evidence of practice on the ward tends to suggest that the internal world of the dementia patient can be assumed to be of no consequence. However, this should be a matter of concern because this claim means in effect that the patient is treated as a non-person. Autonomy and personal responsibility are largely removed from the patient when medication is viewed and used as critical to the management of challenging or abusive behaviour. This tends to simplify the carer's role, by encouraging them to take responsibility for or control over the patient with dementia, but it has negative consequences for the patient's dignity and identity.

Included in their guide for registration and inspection staff, Jean Elgar and Mary Marshall make the following pertinent reference to the use of medication in care planning:

The use of drugs within any long-term care resource is usually an emotive issue and can be influenced by the knowledge and skills of the service providers and the medical personnel who give a service to the person with dementia. Although

the prescribing of drugs is an exclusive prerogative of the doctor, it can be tempting for staff to look to drug-related responses for situations, which they feel, are exceeding their caring abilities. (Elgar & Marshall 1998)

On the ward the doctor was the prescriber of medication, but the decision to call the doctor for the purpose of prescribing was the prerogative of charge nurses. 'Doctors usually rely on nurses for accurate and factual information about patients, including the effectiveness and side effects of drugs prescribed' (MacDonald & Teven 1997).

These facts highlight two issues; *first* the need for nurses to be knowledgeable, up-to-date and adequately trained in the use and effects of drugs used for treatment of dementia patients; *secondly*, the need for nurses to understand and be tolerant of challenging behaviour and to explore alternative and more effective methods of managing such care.

In relation to the first point, for example, Kate Allan in a paper on wandering, also draws attention to the fact that in some cases wandering may be happening as a side-effect of medication given for unrelated reasons. It may also be a response to distress caused by medication (Allan 1994). It is difficult not to conclude that nurses were insufficiently well trained and/or experienced in assessing the impact of certain types of medication on patients on the ward. However, there was ample evidence of carers managing problematic behaviour of patients by resorting to the administration of drugs as has already been pointed out.

In relation to the second point, namely nurses' understanding and tolerance of challenging behaviour and the need to explore alternative and more effective methods of managing such care it was obvious that they had inadequate training to deal with these issues. Because the formal, informal or ongoing development of staff members did not provide them with opportunities to develop the skills and understanding to manage challenging behaviour in alternative ways, carers did tend to look to drug-related responses to handle situations that exceeded their abilities, as was seen above in the case of Mrs Kirk.

Further, it was never quite clear if carers perceived caring for this particular group of patients as an area of speciality, made more effective through access to certain knowledge and skills. Rather, there seemed to be an assumption that the care approach necessary was mainly '*a lot of common sense*', reinforced by the fact that there was rarely any feedback from patients as recipients of care. There seemed to be a certain expertise that most carers assumed, often based on the experience of having known an elderly relative, family friend or neighbour who had dementia without any consideration for the individuality of persons or the varying ways in which the disease can impact on individuals.

The use of anti-psychotic drugs on people with dementia who exhibit challenging behaviours; and whether or not nurses' tolerance and understanding of such behaviour contributes toward an increased use of drugs continues to receive some attention in the

literature on dementia care. Findings indicated that lack of training and education in the management of challenging behaviours in people with dementia, including negative attitudes and 'ageism', and lack of knowledge of alternative approaches in the management of challenging behaviours were key influences on nurses' understanding and tolerance of challenging behaviour (MacDonald & Teven 1997, pp. 21-22).

The findings of this study based on observations of nursing practices, with regard to the management of difficult behaviours of patients on Karibu Ward, are confirmed by a study by MacDonald and Teven (1997, p. 19), which suggested that the poorer the nurses' understanding and tolerance was of problematic or challenging behaviours, the higher would be the use of anti-psychotic drugs. The outcome of their study was not conclusive, although the findings do appear to give substance to their hypothesis. This study supports the judicious use of such drugs, but only as a last resort, rather than as a first choice for managing difficult behaviour. Almost without exception, and underpinned by a person-centred approach to care, research and studies over the past decade strongly support the view that nurses who are knowledgeable, caring, understanding and innovative are ultimately more effective in the management of challenging behaviours than those who primarily rely on the administration of drugs for the management of difficult behaviour.

8.7 Custodial Approach to Care

Despite carers' obvious commitment to the physical needs of patients, there were situations and incidents that tended to reflect a diminished quality of service to patients. These situations usually occurred due to an apparent lack of understanding of dementia and perceived time constraints bringing pressure to bear on how staff engaged with patients. This was most consistently evident in the way patient mealtimes were managed, as the following discussion will show.

8.7.1 Management of Patient Mealtimes

Food and drink play a vital part in the lives of all people, irrespective of age, nationality or income levels. In possibly every culture known, mealtimes are experienced as a shared pleasure, based on certain rituals, such as the preparation of food and the eating environment. However, and perhaps most ironically, hospital food has generally never been acclaimed for being appetising or aromatic! The experience of eating, and mealtimes, in healthcare settings have been a source of dissatisfaction

for many people over the years. From observations on Karibu Ward, mealtimes seemed to be perceived by carers as tasks to be completed within a tight time frame rather than as a potentially pleasurable or therapeutic experience for patients.

Thus, as already discussed in Chapter 6 meals were served three times a day and were brought from the hospital kitchen in meal trolleys and served by staff in the dining rooms. Some patients were seated at tables that accommodated 4-6 people. The least mobile patients were fed where they were seated in lounge or mobile chairs in the sitting room. Only those patients who could make some attempt at feeding themselves were seated at the tables. Care was taken not to seat certain patients together, or too many at a table, in order to avoid disruptive behaviour such as the stealing or throwing of food. However, no conscious attempt was made to seat people together who enjoyed each others' company, and there was no evidence to suggest that carers knew which patients might wish to do so.

There were several factors associated with meals and mealtimes worthy of note from the point of view of their impact on patients. Mealtimes accounted for approximately an hour and a half of the patients' day. Data collected was based on observations of mealtimes, chosen at random, over several months. Almost every visit to the ward included a mealtime, and observations were combined with numerous conversations with staff regarding food choices, the general atmosphere at mealtimes and other issues associated with feeding patients.

Dining tables were devoid of coverings and condiments. Care was taken to ensure that all potentially hazardous objects such as salt and pepper cellars were removed and, as a result, patients were not given the choice of flavouring food to their personal taste. Meal trolleys were left in the corridor while meals were served. The reason given for this was to guard against the possibility of patients being accidentally injured by a trolley. This also meant that patients did not get the aroma of foods being served to them, to enhance the pleasure of eating.

Mealtimes were one of the high activity points of the day, and the atmosphere seemed to gather momentum as patients were mobilised and meals were served. In terms of a serving procedure adopted, the aim seemed to be to first serve those patients who could self-feed, to get them started. Carers took responsibility for serving those patients allocated to their colour-coded group. This in effect meant that some self-feeders at a table had food before patients who belonged to the other colour-coded group, which led to disruptive behaviour in the form of frustration, food stealing and the creation of a mess. The procedure was to serve one course at a time, keeping other

courses out of sight until the patient was ready, and to avoid the possibility of a mess, as patients sometimes tended to grab food and dishes.

Carers made the decisions for patients regarding choice of meals by filling out menus for a week at a time. Choices seemed to be primarily based on the patients' ability to chew and swallow, and since the majority of patients did not have teeth and some had difficulties swallowing, food was minced, grated or liquidised to guard against problem feeding. As a result, food often looked the same from day to day, even though the menu supposedly changed from week to week. The texture of the food appeared mushy and lacked appeal in presentation. For example, it was difficult to distinguish between semolina and the liquidised fish dishes. This was not helped by the fact that both foods were served in the same type of bowl. There also appeared to be some inconsistencies between the actual meals ordered for patients and those served up by staff. This situation was managed by simply making do with what was available: that is soup or sweet dishes, which were not needed by other patients. The alternative was for a staff member to go to the kitchen for the correct meal – a process that was considered too time consuming and disruptive to the task at hand. Tea was served in plastic cups with lids, from a large teapot on the trolley. The strength of the tea was the same for everybody, the main concern being to ensure that it was not served too hot and to guard against over-filling the cup.

Quality control or standards of choice, texture and presentation of food seemed to go largely unnoticed by carers. The fact that patients were unable to express their reluctance to eat or preference for a particular food was not deemed a concern since it was presumed not to make any difference to patients. This perception was frequently reflected in the attitudes of staff and also in the words of one carer who said "*they won't know anyway.*" In terms of the general environment, it was clearly seen to be a challenge to keep the dining area reasonably clean and tidy. Tables were always wiped after meals and the floor mopped because furnishings tended to become dirty and sticky from an assortment of food remains and, in particular, from patients who were feeding themselves.

8.7.2 Limited Patient-Carer Interaction

The quality and quantity of verbal and non-verbal communication during mealtimes was also of significance. As meals were served and patients fed, or supervised as they fed themselves, verbal interaction between patients and carers was usually in the form of brief instructions, for the purpose of orientating patients towards

their food. While interactions or instructions were never brusque or curt, neither could they be described as particularly sensitive. Occasionally, some carers made derogatory remarks about the food, in the presence of patients, implying it did not matter or that patients didn't understand.

Carers usually spoke to patients to encourage or prompt them to continue eating, but did not appear to be in the habit of making patients aware of the food by naming specific items such as vegetables, or describing specific dishes. There were no conversations or discussions about food or cooking or of any other items that tend to be typically associated with relaxing at mealtimes. Carers sometimes talked to each other while feeding patients and, usually, these interactions conveyed an unexplainable sense of urgency about getting the food into patients and getting the task finished within a limited period of time.

To the onlooker mealtimes usually seemed rushed and time-constrained, leaving little room for individual preferences or eating habits. Even on occasions of family visits, when a few patients had the pleasure of being helped by family members with feeding, the time schedule of serving the meal and tidying up inside a 25-30 minute period was always maintained. The assistance of family members seemed to be appreciated as an extra pair of hands rather than for its possible comforting or therapeutic value for patients. For example, the husband of one patient frequently came to feed his wife her lunch – a gesture of assistance much appreciated by staff members. The fact that the patient recognised her husband and struggled to speak to him over lunch, or that he was aware of her preferences in food, did not seem to be of significance in the context.

Meals and mealtimes were possibly one of the few remaining pleasurable activities for the patients on Karibu Ward, yet they appeared to have become primarily a repetitive exercise for carers. Because mealtimes were time constrained and conducted or managed with a sense of urgency, this caused difficulties for patients in several ways. Those patients who were able to feed themselves, were usually not given enough time to finish meals at their leisure. If all other patients were fed and the self-feeders were still eating, carers usually helped them by hurrying them along to finish eating.

Patients on the other hand who needed assistance with meals were often fed at a pace more suited to the carer than the patient. The lack of conversation or interaction between patient and carer at these times tended to dehumanise the encounter. The fact that carers were largely unable to communicate with or were limited in their ability to

do so with patients did not help matters. Like many other practices and routines on the ward there appeared to be a certain predictability and monotony about the food served to patients. It is not suggested that the food was lacking in nutrition, but the lack of choice, apparent blandness and unappealing presentation seemed to reflect a lack of sensitivity in care for patients. While a patient might not have been able to verbalise choices in food, or to remember choices made hours or days earlier, it is possible that this problem might have been overcome, at least in part, by giving the person a choice at the point of serving the meal. For example, a patient could have been shown a bowl of porridge and another cereal from which to make a choice for breakfast.

There is much evidence to suggest that patients' personal preferences in foods were not taken into account or their preferred eating habits known or considered. For example, some patients might choose to eat only one rather than several courses at mealtimes. Patient preferences were overlooked and replaced by the ward routine of serving all patients their meals at the same time. This process disempowered the patients, by the imposition of institutional practices for the convenience of ward management by the carers. This process also reinforced a view that all the patients were the same and that their needs could be catered for in the same way, thus reflecting a disregard for the uniqueness of each person as an individual. In short, this was an example of ward practices and policies, as well as carers' needs, taking precedence over the needs of the patient.

In conversations with carers it was evident that they were aware at times of hurrying patients through their meals, but this was generally rationalised on the basis that the kitchen trolley, stacked with dirty dishes and cutlery, had to be ready for collection by a certain time. At no time did any carer suggest that it might be helpful to explore alternative methods of catering for patients' meals. From observations many aspects of mealtimes seemed unappealing to both patients and carers, yet the routine was adhered to from day to day without change. While carers seemed to accept this activity as simply an aspect of care without much reflection or consideration of the impact on patients, they were much more aware of deficiencies in other aspects of patient care. For example, carers were particularly vocal in expressing their condemnation of the quality of equipment in use on the ward, such as hoists and wheelchairs used when bathing/toileting patients. However there were other aspects of these activities that carers sometimes seemed to overlook.

8.8 Further Evidence of a Warehousing Approach to Care

It was not uncommon on the ward to hear relatives of patients sing the praises of carers from time to time during visits. Sentiments of admiration such as *oh I just don't know how they do it*, or *I just couldn't do that sort of work*, often seemed to mask a certain ambivalence, based on feelings of disgust, shock, pity and embarrassment, triggered by the awareness of unpleasant smells on entering the ward or evidence of incontinence. According to Jenkins (1999), 'faecal incontinence takes all the participants on to primitive ground', triggering predominantly negative instincts, which may be acted upon, repressed or redirected and therefore require attention and appropriate management.

As in the Hughes and Wilkin (1987) study on the physical care of patients and their quality of life, toileting rounds on the ward were reported to be regimented and often lacking in privacy, a consequence of the need to toilet large numbers of incapacitated people in a short space of time. As observed in the Hughes and Wilkin study, carers on Karibu Ward could not be described as brusque, cold or uncaring; rather the situation highlights the conflict that can arise in communal settings, between the need to get the task done and ensuring that the dignity of the patient is respected.

It might be obvious that toileting patients according to need is more likely to go some way toward preventing or reducing incontinence among them, but carer adherence to toileting rounds seemed to be primarily a time-managing strategy that failed to give priority to patient comfort. The fact that the toileting round makes public an otherwise personal and private activity can be embarrassing for patients, due to lack of privacy and feelings of embarrassment, but seemed of little concern to carers. While regular toileting of incontinent patients may constitute good care, the issue at stake here appeared to be adherence to practice and routines for the convenience of staff rather than patients. While recognising the fact that routine is actually important and can give patients with dementia a sense of security and control over their environment, a more person-centred approach would require greater flexibility in routines and schedules. For example, a more person-centred approach might allow and indeed encourage patients 'to establish their own routine and then to support this through a structured and dependable programme to which changes are introduced slowly and only after careful preparation' (Redfern & Ross 1999, p. 556). While this approach could be very time-consuming and might only be successfully established after much trial and error, it has the potential to ensure that the patient will feel more in control of themselves and their environment and that their privacy is respected.

However 'accidents' did occur and it was not uncommon for carers to start the day with a clean-up operation following an incident of faecal incontinence. Such a task required a calm, professional approach. While the goal of carers on the ward was to have the patients clean, dry, dressed and sweet-smelling as soon as possible, reassuring embarrassed or upset patients is equally important, according to Jenkins (1999, p. 18). The needs of patients in this regard seemed to be generally overlooked, as will be discussed in Chapter 9. It was also noticeable that the need for carers to recognise and deal with their own feelings of possible disgust, nausea and perhaps anger usually went unnoticed. This issue will be raised again in the context of carer training in Chapter 10.

Similar to the scheduling of the toileting rounds, the patients' bathing routines were determined by policies and procedures that were chosen by carers without patient consultation. Failure to consult the patient or family about preferences and past patterns of bathing has often been highlighted in the literature as an approach that can undermine the delivery of good care. A bath book containing bathing times and dates for patients' baths was checked each day and approximately three patients were bathed each day in the mid-morning or afternoon. In general the bathroom was viewed as something of a *battleground*, and the task of bathing as a *challenge* by carers. It was observed that bathing difficulties sometimes started at the point when the carer approached a sleeping patient with the hoist. Patients would not only fail to recognise the carers but would also appear bewildered and confused as to the purpose of the hoist. This situation often became a trigger for the patients' disturbed behaviour.

The issue of timing seemed to be particularly significant with regard to bathing patients. For example, if patients' daily patterns in terms of when they are most alert or attentive or quite sleepy and sometimes tending to be irritable were taken into account, then selecting the bathing time best suited to their state of alertness could make the process more relaxing and less disorientating for patients. In agreement with Rader, the bath-experience should be altered to fit the individuals' needs and ability to cope, not determined by an assigned day of the week (Rader 1995, p. 56).

With regard to approaches to practice on the ward, it is suggested: first, that carers could manage the tasks of toileting and bathing patients by having a better understanding of how confused and frightened some patients can be when faced with even the most mundane, routine tasks. Secondly, it is important to remember that everybody is different – some people may feel that one bath a week is enough, while others may prefer a bath every day or every other day. Some may actually dislike baths because of a fear of being left on their own in the water. Thirdly, the policy of scheduling baths on specific days and at specific times

should be re-evaluated, based on patients' needs. While it may in fact be very difficult to achieve, it does seem important that carers find individual routines that work for each patient. Fourthly and finally, carers need to be sensitive and responsive to the vital difference between taking over and doing everything to and for patients as distinct from working with them.

8.9 Conclusion

This chapter has been concerned with the prioritising of one element of care at the expense of others on Karibu Ward and the implications of an approach that lacks a holistic approach to patient care. The carers observed held to the view that they should basically do everything for the patients and they appeared to be more focused on patients' deficiencies than on the abilities, however fragile, they might still retain. It has been argued this view of patients has implications for the way staff members approached the delivery of care, putting prime emphasis on keeping the patients comfortable – in a physical sense. Carers were adept at catering for the physical needs of patients, but there is little evidence to support the view that they actually understood severe dementia or the fact that the patient might have emotional and spiritual needs that they were unable to articulate.

Carers assumed that patients were not in touch with the reality around them – or if so, only to a very limited extent. The implication of this was that there was little point in trying to do anything other than keep them physically fed, washed, toileted and generally comfortable. The danger with this perspective is that it tended to reduce the person to a feeble physical body, for which carers became caretakers doing things to patients rather than with them. This has been referred to as the 'nursing tradition' by Kitwood (Chapman & Kerr 1995, p. 19). In this chapter discussion indicates that carers view patients primarily in terms of their vulnerability, dependency and lost abilities. The key implications are that all patients are then seen to have the same basic fundamental physical needs, encouraging a 'warehousing' approach to care. This chapter has been concerned with how care is defined and the implications arising from a warehousing approach to care that seems to have its roots in a medical model and a diminished understanding of patient needs.

What is perhaps somewhat surprising is the fact that all patients on the ward were in the throes of dying or likely to die within a few years at most, yet care of the dying seemed to be limited to basic nursing duties. There seems to be a need to consider hospice-type care for these patients, which would require carer training, and a change in hospital and ward

policies, as well as a restructuring of ward layout and design to cater for patients' needs. These points will be explored further in chapter 10, when further consideration is given to factors that influence the delivery of care.

CHAPTER 9:

How Carers Managed Psychosocial Aspects & Special Challenges in Care Delivery

9.1 Introduction

This chapter will focus on the two remaining themes to be developed, which are communication and managing patients with disturbed behaviour. The issues of communication being discussed are primarily focused on how the psychosocial needs of patients were addressed. Communication issues will also permeate the second theme to be developed, which is concerned with how carers managed patients with what was identified as 'difficult behaviour'. While communicating effectively with patients can be assumed to be an essential element of care delivery, communication with such patients raises complex issues in nursing care practice.

This chapter is concerned with how certain activities were managed and more specifically how carers and patients interacted during the process of care. The approach adopted was underpinned by the belief that 'nursing is an interactive process where the quality of the relationship between the nurse and the patient can have marked effects on the physical, social and psychological wellbeing of the patient' (Redfern & Ross 1999, p. 188).

In this chapter the following issues are explored:

- therapeutic nursing encounters between carers and patients, seen as positive aspects of patient care
- specific examples of how ineffective communication strategies appeared negatively to affect care outcomes
- how carers prioritised and met the psychosocial needs of patients
- carers' expressed assumptions about 'what's in the patient's best interest' — notwithstanding the sincere commitment of the carers involved
- the care management of patients with challenging behaviour as illustrated by a case-study.

9.2 Therapeutic Encounters

Developments in the fields of sociology and psychology have contributed to society's increased understanding of human nature over the past century. They have also highlighted the limitations of the medical model when applied to nursing care practice, and the need for alternative approaches to patient care. Humanism and a holistic approach to people as persons are two of the most influential concepts that have emerged and influenced models of nursing over the past three decades or so (Pearson, Vaughan & Fitzgerald 1996, p. 48). Unlike the medical model which directs attention to the disease, its diagnosis and treatment, a holistic approach takes account of the fact that 'the individual always responds as a unified whole and individuals as a whole are different from and more than the sum of their parts' (Pearson, Vaughan & Fitzgerald 1996, p. 48).

This shift away from reductionism and toward holism is also reflected in the changing nature of approaches to group and community work over the same period. For example, the development of therapeutic communities has significantly shifted the management of mental hospitals away from the influence of doctors and toward involvement of its residents or patients in managing their daily life. In this way the hospital becomes a therapeutic community for the purpose of re-socialising its members back into society (Whitley 1992, p. 64). Bloor, McKeganey and Fonkert (1988) have identified numerous aspects of practice utilised by staff in a range of different therapeutic communities in hospitals. They 'conceive of therapeutic work as a cognitive activity which can transform any mundane event in the community by redefining that event in the light of some therapeutic paradigm' (Bloor, McKeganey & Fonkert 1988, p. 5). They elaborate further by referring to an event as an improved or less pathogenic way of relating to others.

For example the majority of patients on Karibu Ward seemed out of touch with their immediate environment most of the time — in terms of relating to carers and/or remembering how to perform even the simplest of tasks. However, the behaviour of these same patients was quite different whenever they participated for example in music evenings, which formed part of special celebrations such as the Christmas Party and Burns Night. On these occasions patients who were otherwise non-responsive could be observed keeping time to the music and joining in the singing. This could be described as a normal or less pathogenic way of relating (Bloor, McKeganey & Fonkert 1988, p. 5). There were other examples from time to time of patients' capacities or tendencies to engage in 'normal' behaviour. For example, some carers were willing to turn a 'blind eye' to the fact that one patient, in particular, would cadge cigarettes off relatives during visits, which she was

allowed to smoke under the supervision of family members. While there was a no smoking policy for patients, the fact that this patient was allowed to smoke and carers were willing to bend the rules reflected their understanding of the pleasure it brought to the patient to engage occasionally in a habit that was commonplace for her before admission to the ward.

In discussing the role of nurses in the detection, assessment and care of an elderly patient with depression, Colin Hughes identifies the therapeutic relationship that exists between carers and patients as a fundamental element of the nursing approach. Hughes goes on to explain that 'a key part of this therapeutic relationship is the personal qualities of the nurse... warmth, empathy (and) genuineness' (Hughes 1999, p. 574). These personal qualities, which were identified by Carl Rogers in his work on client-centred counselling (Rogers 1967), refer to the nurse's ability to be warm, positive and accepting of patients as well as having an ability to see and understand the world of the patient.

The following example from Karibu Ward seems an appropriate illustration of the sensitivity of a caring approach and desire to connect with the world of the patient.

A charge nurse had responsibility for buying the Christmas presents for the patients and went to a great deal of trouble to find something that she thought each patient would like. One patient had been a very keen and accomplished golfer in her earlier years, a fact known to the staff member purchasing the gifts. She took a great deal of trouble to find a small print of a golfing scene from St Andrews Golf Course and framed it to present to the patient. The staff member watched eagerly as the patient opened the present, but the patient looked blankly at the picture. The scene did not appear to evoke any memory from the past for the patient. The staff member proceeded again and again to explain what the picture was about, in the hope of jolting the patient's memory, but to no avail. The patient eventually put the picture down by her chair and the staff member gave up on her attempts to help the patient make the connection between the scene in the picture and her golfing days.

This example reflects the consistent tendency of one nurse to go 'beyond the call of duty' in her efforts to meet patients' needs. Her knowledge of the patient's biography enabled her to personalise care, in the hope of triggering happy memories for the patient from her past. Despite the fact that the patient did not appear to recognise the significance of the golfing scene, the nurse did not conclude that it was a pointless exercise — despite her obvious disappointment. This appeared to be because the nurse was genuinely committed to adding some variety and pleasant experiences to what she perceived to be their dull and bland day-to-day existence on the ward.

Despite the diminished capacities of some patients, there were other examples of positive encounters between patients and carers, based on friendship and humour.

For example, Debbie was a junior nurse assistant, who had worked on the ward for two years. Her cheery disposition and tendency to tease some of the patients made her a very popular member of staff. She had a particular bond with one

patient, Beth, whom she related to in a very warm and friendly manner. When Debbie discovered that she was expecting a baby she shared the exciting news with Beth. From time to time Debbie would remind Beth that she was expecting the baby, which became quite a talking point on the ward as the weeks went by. Despite Beth's tendency to forget her way around the ward and the names of family members, she was consistent in showing genuine concern for Debbie and her baby. It was often quite touching to hear Beth reassure Debbie that 'everything would be okay with her baby'. This seemed to be a truly genuine friendship based on mutual care and respect. It highlighted the patient's ability to understand her environment and respond appropriately, despite obvious diminished capacities to communicate effectively at other times. In addition it reflected how the personality and natural qualities of the carer had the potential to greatly improve interactions with patients and the general atmosphere of the work environment.

The scenarios explored above are positive examples of 'sociability (civility, humour and socialising), reciprocity (friendship, sharing and solving problems), which have been identified as central to the relationship between carers and patients and communication challenges in old age' (Le May 1999, p. 189). These elements emphasise the centrality of communication to the process of care and the goal of therapeutic relationships. However, the following examples reveal how ineffective communication strategies appeared negatively to affect care outcomes.

9.3 How Ineffective Communication Strategies Appeared To Have A Negative Effect On Care Outcomes

This chapter is concerned with discussion of issues in the light of an extended definition of nursing care that incorporates not only what is done but the *way in which it is done*. For example, according to Keegan, bathing a patient may be considered a reasonably straightforward task 'but if you add to the equation that the person having the bath could be physically frail, disorientated in time and place, and also afraid of water, then this simple task can seem an impossibility, yet it is a daily reality for both qualified and auxiliary nursing staff who work with people who have dementia' (Keegan 1998). Keegan goes on to explain that while carers may have been trained in the procedure of assisting with the task of bathing, it cannot be assumed that they also have the knowledge and skills to communicate in an effective way with a potentially frightened patient.

It is of interest to note that no carers made any reference – specific or general – to the importance of communicating with patients when asked what they considered to be priorities in patient care. As already discussed, carers identified the more physical needs of patients as

priorities, and to these they allocated most time. From observations however, verbal interactions between carers and patients appeared to fall into two categories: those directly related to the tasks of feeding, washing and bathing, for example, and then some social engagement with patients in the form of 'conversations', which primarily occurred during the quiet or down times on the ward. Because dementia significantly diminishes the patient's capacity to communicate, some carers often seemed to struggle in their attempts to communicate with them.

For example, the routine of transporting a patient by hoist to the bathroom became a challenging task. Despite the carers best efforts to reassure a patient, the situation was fraught with difficulties as the following scenario will show.

A patient had been asleep in her chair and when woken by a carer to have a bath she seemed quite disorientated. While the carer did explain to the patient that she was taking her for a bath, there was no obvious indication from the patient that she understood or even recognised the person speaking to her. As the carer transported the patient she tried to reassure her — while attempting to manoeuvre the hoist in the direction of the bathroom. It was necessary for the carer to move from the front to the side and then to the back of the patient during this process, which meant she was not looking directly at the patient when speaking to her. Because the patient did not understand the instructions given, such as, 'hold on' and 'don't move, you will be okay', her fear escalated to combative behaviour. The carer found it necessary to call for help, which in effect meant that the patient was 'overpowered' — it becoming a two-against-one situation. Understandably, in this and similar situations when patients did not seem to understand or follow instructions, it was observed that the process of repeating instructions often resulted in carers feeling frustrated and sounding tense, the situation becoming unpleasant for all concerned.

It should be noted that the carer in the scenario above was inexperienced, adding significantly to the difficulties encountered. However, this incident illustrated several other issues which appeared to impact on patient care in other situations where other carers were involved. Had the carer taken into account the fact that the patient was disorientated on waking up and had chosen to give her a cup of tea and a little time to become familiar with her immediate environment and its people, the situation might not have become an incident.

Because care was routinised on the ward, in practice this meant that there was not a culture of taking the time to meet the specific needs of patients with sensitivity, as in the example above. This does not mean that carers were unfeeling or curt as a matter of course, but rather that getting the work done seemed to take priority over sensitivities in practice that might otherwise significantly enhance patient care.

Whereas in other care settings, patients on the ward are usually served cups of tea on waking in the morning, on Karibu Ward this was not the case.

It would appear that this case reflects how care was prioritised and more significantly it illustrated the carers' lack of or limited understanding of how dementia affects patients. While it is well documented that a patient's failure to respond immediately to a question, or instruction, can be for a whole variety of reasons such as, needing time to understand what was said, struggling to remember words or connect them in the right order to make a sentence, this did not seem to be taken into account. Carers would more often assume that the patient's problem was a hearing difficulty rather than lack of understanding and would therefore tend to repeat instructions in a louder voice resulting in a tense atmosphere.

There were other situations in which carers did not appear fully to appreciate the need for more effective communication with patients. For example, carers would often assume that patients who stopped eating half way through a meal or showed little interest in the food remaining on the plate, had simply had enough to eat. The more likely explanation was that the patient had momentarily forgotten what they were doing, or the purpose of the food. A more appropriate management of these occurrences would have been for the carer to sit beside that patient and gently remind them where they were, what they were doing, to comment on the food and encourage the person to proceed with eating. The practice however was more often for carers to say to patients 'come on, eat up', or 'have you had enough?' Patients never seemed to respond to this question nor was it clear that a response was expected.

Emphasising the importance of communication as a basic skill in nursing care, Pat Ashworth (1998, p. 9) believes that 'unless nurses communicate, they can neither assess the patient's need for care, plan care effectively, carry it out, nor evaluate it'. Verbal interactions represent only a limited part of how we communicate, 'as in reality over 80% of our communication is non-verbal... It is no different for the person with dementia, except that as they increasingly encounter difficulties in expressing thoughts and feelings in conversation, there is a tendency to rely on non-verbal means' (Goldsmith et al 1997, p. 6). What the literature advises is that carers have to become adept at finding out what the patient wants — to communicate by observing and interpreting gestures, facial expressions and aspects of non-verbal communication.

Given the complexities involved in communicating effectively with patients living with dementia, it is strongly recommended by various sources of expertise in the field that carers need additional and specific training to work creatively and constructively with these patients. Evidence from observations on the ward would suggest that experience did contribute significantly to fine-tuning the eyes and ears of carers to more effectively meet the needs of patients. However, in the absence of adequate and appropriate training, assumptions

about care practices, based solely on experience, may in fact prove erroneous and inadequate, as the following discussion will reveal.

9.4 Assumptions About Care Practices

In her exploration of creative and compassionate approaches to individualised dementia care, Joanne Rader believes that even patients who appear to be in a vegetative or non-responsive state still retain an ability to communicate many things, such as discomfort or pain (Rader & Tonquist 1995, p. 22). This view, which is also supported by other observers in the field of dementia care, seems consistent with the experience of some carers on Karibu Ward. In general terms the more senior and experienced nurse assistants on the ward seemed to know the patients well enough to be able to detect when a given patient might have been feeling unwell or anxious. These carers appeared to have strong bonds with the patients, as was often reflected in the teasing and humorous ways of communicating.

One carer in particular, who took a 'no airs and graces' approach to care, appeared to have real confidence in her work, based on years of experience. When asked how she could detect if a patient might be feeling upset or low in spirit, she said she could usually tell what they were feeling, by their eyes. This carer seemed to be adept at reading or listening to the patients' non-verbal messages and was skilled in interpreting their behaviour. This approach and these skills are consistent with Rader's specific reference to this particular way of identifying patients' feelings. She states that 'as you get to know the resident, the eyes (the "windows to the soul") will communicate; caregivers learn to "read" the message and alter care based on that observation. Having a consistent long-term relationship with the resident is especially helpful in this' (Rader & Tornquist 1995, p. 22).

There was consistent evidence to suggest that the carer in question had developed skills of observation and the ability to respond accurately to patients' needs based on reading their non-verbal communication. She frequently made reference to the fact that she was not formally trained but believed that she did a very good job without training. She was robust and energetic in her approach, which commanded a certain respect. Her example often seemed to be an incentive to other carers to remain positive about their work. The staff member in question also took particular care in ensuring that patients were well presented at all times. When asked about this aspect of patient care she said:

'I think it very, very important that the patient look their best even if they do not feel their best. They can't do it for themselves so I am a strong believer that we should always do our very best to have the patient looking good - clean, hair

combed, in matching clothes - I don't believe in patients sitting around in dressing gowns ... and you know another thing, I hate to see women wearing socks and bedroom slippers with their day clothes. No that's not right! I would not like it if I were them. Presenting them well is about dignity, isn't it? ... Besides, it's important for the relatives of the patients to see that we care about the patients and have them looking nice'.

There are, however, differing opinions about the significance or value of this emphasis on the appearance of the patients. On the one hand a positive interpretation can be placed on the fact that this staff member took a very specific interest in each patient and appeared to know their ways in terms of what they liked to wear and when they needed reassurance or support. She took personal pride in presenting them well-groomed and looking their best. She seemed to care for the patients as she might an elderly aunt or relative. This kind of personalised interest and approach finds support among some nurse theorists, psychologists and social workers: for example, those who advocate an individualised approach to care, as does Tom Kitwood and all those who have extended his theories on care.

On the other hand there is another body of thinking which questions the motivation behind the preoccupation of staff attention to the presentation of patients. Giving a fairly depressing view of life in a nursing home in England, which followed earlier studies in the USA, Nolan (1996, p. 57) 'suggests that the motivation behind the activity of the unqualified care staff, who give the majority of 'hands on care', is to present the 'lounge standard patient' - an individual who is smartly attired and looks neat and tidy whilst on public display in the lounge, a presentation of a 'well-ordered body' symbolised a job well done'.

It has already been established that carers on Karibu Ward including the carer discussed above, did take pride in their work and felt a sense of accomplishment when required daily tasks were adequately completed and on time. For example, seeing their patients looking nice and well-groomed gave carers a sense of satisfaction. Carers on the ward would have found it offensive that they might simply be motivated to present the lounge standard patient devoid of any specific interest in individual patients, as suggested by Nolan.

However, carers on Karibu Ward assumed and did not question whether it was in the best interests of the patients to be dressed in day clothes, including pantihose and shoes from early morning until bed time each day. No consideration was given to the possibility that some patients might have preferred to wear and felt more comfortable in a dressing gown and slippers — especially when not expecting visitors or when particularly unwell. Physical appearance seemed to take priority over patient comfort. For example it was not considered that wearing pantihose all day when leading such a sedentary life might, in fact, be actually unhealthy for patients. These and similar questions should normally be covered in carer

training, but there was not a significant culture of staff development on Karibu Ward apart from an initial on-the-job training period for each carer. As a result there did not seem to be a forum for staff to discuss or reflect on the strengths and/or limitations of current practices.

There were other cases of encounters between carers and patients, which tended to reflect some uncertainty regarding the appropriateness of carers' responses. For example, most carers did not seem to know how best to respond to a distressed or agitated patient. Responding appropriately to patients expressing strong feelings seemed to be unfamiliar territory for most carers. These situations were frequently managed by seeking to distract the patient with offers of a cup of tea, or by taking the patient for a walk. This approach momentarily calmed the patient but did not resolve the issue and (unintentionally) appeared to deceive the patient in order to obtain compliance. Some carers took a different approach, but not necessarily a more effective one, as the following example shows.

Annie – a patient – became increasingly agitated, as she shuffled up and down the corridor looking for her mother.

Annie: I want my mother, I want my mother, where is my mother

Nurse: (In a calm voice said) Annie, you are 75 years old, there is no way you can expect to be able to see your mother.

This dialogue was repeated a number of times and the nurse eventually managed to get Annie to sit down and be quiet.

Having observed this encounter, the nurse's response to Annie did seem somewhat harsh. However, her response requires some teasing out and can be interpreted in a number of ways. It was evident that the patient was disturbed and was struggling to communicate something of how she was feeling. The nurse did not explore the patient's feelings with her but chose to respond by reminding the patient of the reality of her absent mother. So, while it may seem somewhat insensitive or even cruel that the nurse did not explore the patient's feelings, therefore failing to empathise with her in her struggle, reality theorists would probably applaud her approach. Based on reality therapy training it has been common practice for some time to provide programs and teaching aids that assist patients with recall and environmental orientation. For example, this approach stresses the importance of providing visible reminders in the form of pictures that help patients to stay in touch with facts such as the time of day, the day of the week, the season and the like. From a reality therapy perspective which emphasises the importance of assisting the patient to stay in touch with their immediate environment, the nurse's response may well be affirmed as good practice based on her reminder to the lady that it was unrealistic to expect to see her mother. The nurse's response could also be described as honest, treating the patient as an adult rather

than a child and in that way being respectful of her. However, the nurse was in fact busy at the time and finding it difficult to concentrate due to the demands of another patient requiring attention. Putting the nurse's response in context it seems that it was more influenced by the pressure at the time rather than from any influence of reality orientation training. However, it would be very far from the truth to conclude that this nurse had a tendency to be insensitive towards patients' needs, because it was she who selected the gift of the golfing picture for the patient as described earlier in this chapter.

So far it has been established that carers seemed unsure how to respond to situations in which patients became emotionally distressed. It has also been shown that a carer's response in a given situation can depend upon a variety of factors such as experience, training and their personal commitment to their work or the demands of work at a particular time. These factors coupled with ongoing staffing issues, restrictive and inadequate environmental design and equipment, as well as carers' lack of awareness of potentially beneficial alternative approaches, tended to result in a less than desirable or satisfactory outcome in certain aspects of care delivery. The implications of these approaches will now be considered from the point of view of how the emotional and spiritual needs of patients could be met.

9.5 Meeting The Psychosocial Needs Of Patients

Meeting the psychosocial needs of patients is an essential part of a 'holistic approach' to care delivery (Marr & Kershaw 1998, p. 286). 'It is suggested that the issue of how psychosocial needs are addressed be dealt with in an integrated manner, central to which is the individual nurse's operational philosophy' (Marr & Kershaw 1998, p. 286). Psychosocial well-being generally encompasses the emotional, intellectual, social and spiritual characteristics of an elderly person, and promoting psychosocial wellness is a key aspect of nurses' responsibility (O'Neill 2002, pp. 241-242). In her discussion on depression in dementia, Fiona Goudie (1999, p. 179) draws attention to the fact that due to the biological and psychosocial factors associated with it, the onset of dementia can lead to a high likelihood of depression in such patients.

Goudie goes on to stress the importance of carers having an awareness of possible contributing factors and sources of effective treatment and interventions. She concludes by reminding the reader of the importance of allowing patients to express their feelings — irrespective of their degree of impairment. 'Fundamentally those who work with dementia sufferers and their families must accept that the dementing person, whatever their degree of

impairment, has a right to experience and express feelings and to have these acknowledged by the people who work with and care for them. Only by acknowledging this right to experience and express emotions, will it be possible to develop our strategies for helping those people who experience feelings, which have become distressing and overwhelming' (Stokes & Goudie 1999, p. 180).

However, it must be recognised that these expectations of carers can be difficult to achieve. As stated by Barnett (1997, p. 6), for carers to spend each day working face-to-face with the emotional pain and desperation of patients can be a draining experience of disempowerment and despair for them. It is against this backdrop and expectations with regard to care delivery that attention will now be directed to the way in which carers on Karibu ward managed to meet the psychosocial needs of patients. Discussion will initially focus on a particular case of a lady named Myra who persistently demanded attention and emotional reassurance from staff.

Myra was almost totally blind and had been treated for depression for many years. She was not able to communicate very well but would often smile, touch people and seemed calmer when in physical contact with others. Myra always looked lost and confused as she paced up and down the corridors through most of her waking hours. She would whimper, complain and whine as she followed carers in and out of rooms wherever they went and whatever they did. At times, this behaviour was experienced as wearisome by some carers, particularly when she followed them into the staff room, interrupting coffee breaks, handovers and meetings. Whenever Myra was rebuked for doing this as she was from time to time, she would get upset and cry. Conversely, whenever a carer simply took Myra by the hand when she tended to interrupt or allowed her to accompany them when appropriate, she would stand by calm and contented, making no demands.

It was generally assumed by carers that Myra's behaviour was 'attention seeking'. Some carers responded to her by perceiving their prime responsibility to her to be that of ensuring that she was fed, toileted, washed and well groomed for her visitors. For them Myra's emotional and psychological needs and insecurities were not perceived to have the same priority or importance as her physical needs. For other carers who would take Myra by the hand from time to time as they went about their duties, her attention-seeking seemed relatively easy to manage. These carers seemed to take a step towards meeting Myra's emotional needs — that is, her need to be near others for reassurance. It is important to note, however, that these carers simply carried on with their duties, while keeping Myra physically close to them. They concluded that her being 'in touch' with them was all that was required to keep her calm and manageable.

Due, it would seem, to the pressure of work and an assumption that it was simply a feature of dementia behaviour, no attempt was made to find the reason for Myra's wandering

or the cause(s) of her distress. Having a greater understanding of her behaviour might have provided more insight into her dementia and more importantly of what particular strategies might be helpful in caring for her. It would seem that some carers on the ward catered for the emotional needs of this patient by default — through keeping her in touch with them without fully appreciating the significance of this spontaneous strategy or setting out on purpose to maintain physical contact with her. There was little evidence to suggest that carers were aware of the importance of understanding wandering as a distressing behaviour for patients. In general carers seemed to perceive it as a behaviour typical of patients with dementia and in itself harmless and for the most part meaningless, unless a patient was also particularly agitated.

The management of Myra's psychological and emotional demands was not discussed. The issues seemed to be much more difficult to define or understand and could not be sorted out within a certain time frame in the same way that physical needs were managed. In agreement with Barnett it was sometimes evident and always understandable that carers who spent each day working face-to-face with the emotional pain and desperation of patients like Myra felt drained by the experience (Barnett 1997, p. 6). Carers' feelings of despondency and negativity were sometimes evident when patients would make their way into the staff room during coffee breaks, when carers hoped for some relief from the demands of work on the ward. In Chapter 10 these issues will be discussed more fully, when attention will focus more specifically on carers' perceptions and experiences of their own role. Meanwhile we will continue to focus on how carers met the social, psychological and spiritual needs of patients, including dealing with feelings and responses to death and dying.

9.6 Other Aspects Of Psychosocial Care

It can be assumed that the majority of nurses in current practice have been trained and urged to be holistic in their approach to care. 'Holistic care means the provision of care in respect of physical, psychological, social and spiritual wellbeing, but perhaps the most challenging aspect of care is the spiritual dimension' (Johnson 1999, p. 603). Ensuring that the spiritual aspects of patients' needs are met has been well established in many models for nursing practice (Pearson, Vaughan & Fitzgerald 1996, pp. 208-210; McKenzie 1985, p. 188). As many people are faced with a serious illness or death they often turn to religion, perhaps for the first time, while others may at that point choose to return to the solace of religious practices that were dominant in the early years of their lives (Cormack 1985, p.

188; Johnson 1999, p. 603). The spiritual is broadly defined here as 'that which gives zest, energy, meaning and identity to a person's life, in relation to other people, and the wider world' (Froggat & Moffitt 1997, p. 225). In this discussion attention is confined to the meeting of patients' spiritual needs through religious practices.

It is important to remind ourselves that people with dementia lose short-term memory, while the function of long-term memory stays intact well into an advanced stage of the disease. In the same way there is now an understanding, based on research and experience of working with people with dementia, that a person's feelings remain intact and these, like long-term memory, can be triggered by events, given certain conditions (Shamy & Harrison 1993): for example the use of symbols and rituals, such as lighted candles, religious music and religious robes. The recitation of familiar prayers or the singing of favourite hymns can give a sense of familiarity and therefore of comfort and security. These things can serve as a strong memory cue and trigger comforting feelings. According to Kitwood, Buckland and Petrie (1995, p. 227) 'being part of a well learned ritual can give respite from feelings of confusion... those who believe in God and continue to have a formal link with God may gain a sense of security through that link'.

Based on the claims of Goldsmith, Kitwood and others in relation to the importance of caring for the spiritual needs of patients and on the body of nursing theory and practice that upholds commitment to an holistic approach to care, the following points are deemed most important in the context of catering for the needs of patients. Firstly, a recognition by carers that the spiritual needs of patients are as important as other needs, and when not recognised or met, the quality of life and care are significantly diminished. Secondly, that carers focus on what abilities the patient may still retain rather than assuming or lamenting their obvious deficits. Thirdly, carers commit to the belief and understanding that patients of whatever religious persuasion or none, may benefit from expression of their religious and cultural customs as well as enactment of significant rituals.

Several patients died and a number of others were dying on Karibu Ward during the period of data collection. There were therefore many opportunities to observe and note practices with regard to the management of these patients. Any reference to dying patients during handover was usually quite brief, always implying that little more could be done for the patient other than keeping them comfortable. While this was possibly very true in terms of physical nursing care, it ignored the fact that much could and should be done to ensure that the patient was assisted to maintain a sense or state of peace and wellbeing as far as possible.

Staff were diligent in meeting the physical needs of patients who were dying. This took the form of regular visits to the bedside of the dying patient, ensuring that they had sips of water, were comfortably positioned and breathing comfortably. However, there was no policy or culture on the ward of carers staying with dying patients during their last hours. In general the attitude of staff was that it would be a blessing if the patient didn't have to linger too long. Since there were no single rooms or other available spaces to which dying patients could be removed, relatives had no choice but to be with the patient in the public setting of a six-bed ward.

It was observed that staff did not generally talk about patients who were dying or had died. For example, on my arrival in the staff room on a particular day, a carer told me that one of the patients had died the evening before. I was taken by surprise and asked if they had expected her death, or if it was sudden. As the conversation continued to focus on the lady who had died, I asked if and how the death of a patient was explained or discussed with other patients. The response indicated that no reference was ever made about the death of a patient to other patients, the assumption being that they would not understand or perhaps would not have noticed. This again reflected a perception of the patients with dementia as people suffering from a disease that renders them incapable of understanding what is going on around them – a medical model perspective. Carers managed these situations by holding onto the belief that:

- it would be a happy release for the patient to die
- it wasn't distressing for other patients because they did not understand what was going on and
- they should keep themselves busy attending to the more physical aspects of care.

It was not evident from observations of practice, what the ward policies were regarding attention to the spiritual needs of patients and the performance of the last rites for dying patients. In addition a number of nurse assistants did not know what the procedure was with regard to notifying pastoral care or chaplaincy services in such circumstances. At no time during the period of data collection was there any evidence of involvement of pastoral care or chaplaincy services on the ward. Religious services were conducted regularly in the hospital by chaplains representing various denominations— and all were invited. However, taking patients off the ward for whatever reason was always perceived to be a considerable drain on staff. Secondly, from having personally attended a number of services during the data collection period it was not evident that they were particularly tailored to the capabilities or needs of the patients on the Karibu Ward. It is possible that a process of

engaging patients in informal religious rituals on the ward may prove beneficial for some. There were no indications that the carers on the ward were aware that meeting the spiritual needs of patients might be a source of comfort, nor was there any evidence to suggest that pastoral care and/or chaplaincy services were aware of the important role they had to play in the life of the ward in terms of the spiritual well-being of patients.

9.7 The Care Management Of Patients With Challenging Behaviour

One of the greatest challenges to carers on Karibu Ward was the management of people with challenging behaviour. People are generally admitted as patients to care settings, especially long-term care, for a variety of reasons, but in particular because of a patient's difficult behaviour, which family members feel they can no longer manage. The management of difficult or problematic behaviour is a major focus of dementia care (Wagner, Terri & Orr-Rainey 1995). Closely associated with the management of such behaviour are issues of physical restraint and the use of other restrictive interventions. The legal implications of such methods, and the potential to cause greater stress to patients, are central ethical concerns in dementia care. Carers are encouraged to find alternative methods of managing behaviour such as aggression or abuse, through the use of therapies, especially relaxing activities, and by creating quiet spaces through appropriate design and planning of buildings (Marshall 1997, pp. 28-163).

The importance of carer training as a critical aspect of understanding and managing problem incidents has also been the focus of considerable debate. For example, Chapman et al emphasise the importance of carers' being encouraged to reflect on a particular patient behaviour that they find problematical and analyse why they perceive it as a problem and to what degree it is their problem and/or the patient's problem (Chapman, Jackson & McDonald 1999). In general they give strong encouragement to carers to recognise that challenging or difficult behaviour may be viewed as the patient's trying to communicate something about their feelings and possible pain. Underpinning this approach is the recognition of the need to develop appropriate skills to communicate effectively with such patients (Goldsmith et al 1997), and the importance of training that encourages an individualised, creative, compassionate approach to patient care (Rader & Tornquist 1995).

Included in the many practical guides that are now available as training manuals, carers are given some specific guidelines regarding the management of a patient during an aggressive episode or outburst. For example, carers are advised to:

- stay calm
- avoid invading the patient's space
- listen and encourage the patient to talk and
- reassure the patient that no harm will come to them (Holden & Chapman 1994).

In practice, however, the degree to which any incident of aggressive behaviour was managed effectively on Karibu Ward appeared to be dependent upon a number of factors, such as:

- carer training and experience
- how behaviour was understood
- perceived time constraints
- how duties were prioritised, as the following example indicates.

9.7.1 Patient Refuses Medication

On one particular morning following breakfast, carers were attending to patients as usual and Brenda – one of the patients – was seated in the open lounge area with a few other patients. She seemed to be generally unsettled, tending to become loud and disruptive. It was difficult to make sense of what she was trying to say or to figure out what was bothering her, but it was very evident she was getting more and more angry and upset. She refused to take her medication. She was supposed to have three different types of medication, which were prepared in liquid form in small measuring containers. She protested loudly and refused to cooperate despite the nurse's best attempts to encourage and cajole her to take the medication. A nurse assistant came to the rescue and also tried to reason with Brenda who by now had become more determined that she was not going to cooperate. The nurse then poured the liquid medication into a syringe-type applicator, which was placed in the patient's mouth to ensure that she swallowed it. Brenda objected to this method of administration and proceeded to spit it out. The nurse assistant then proceeded to restrain Brenda by holding her arms down firmly, thus preventing her from continuing to fight off the nurse. The nurse proceeded to repeat the process while the patient continued to protest – shouting and screaming to be left alone. However, the nurse eventually managed to ensure that Brenda swallowed most of the medication and left her alone to settle and sleep.

The nurse assistant in question was a physically strong woman, who was very good at her work from a practical point of view. She is one of many carers who did not feel it was necessary to have any understanding of dementia as such in order to care effectively for patients. The issue of restraining the patient did not appear to bother her in any way. The nurse administering the medication, on the other hand, appeared somewhat uncomfortable about the incident. During the morning the nurse

came back to check that the patient was okay. A little later I talked with the nurse about the incident.

Me. *How is Brenda now?*

Nurse. *She has calmed down and is sleeping now. I think she is okay.*

Me. *She seemed fairly upset this morning when you were trying to give her the medication*

Nurse. *Yea, it's a problem when patients don't want to take medication. It's not nice when you have to force it on them – but what do you do – if you don't do that. They'd be impossible to manage. (She shrugged her shoulders, then gestured with her hands in a manner that indicated that she felt at a loss to come up with a better approach).*

Me. *So is sedating her in that way a question of choosing 'the better of two evils', then?*

Nurse. *Yea, that's probably true enough. But, there is also the question of her family. You see, she was a professional person in her day and her family prefer to see her sedated – even though they cannot communicate with her – rather than seeing her agitated and aggressive like she was earlier. What I mean is they would prefer to see her sedated than 'climbing the walls' without the medication, which they would find very embarrassing because they remember their mother as a very dignified, reserved and gracious sort of lady. So...*

Me. *So they must find visiting her very difficult?*

Nurse. *Oh yea, it's always upsetting for them because – like many other relatives who come here to visit loved ones – they feel guilty that they are unable to do something for the patient, and they find it distressing to see her condition deteriorate in this way.*

Issues raised by the case:

This scenario raises a range of critical issues about the management of dementia patients. For example: When is the use of sedation justifiable and/or advisable as a method of managing a disruptive/disturbed patient? When might physical restraint be appropriate, or deemed necessary, and how might this be monitored?

There are other questions and ethical issues which also arise, relative to the rights of a patient and his/her family. For example, when a patient refuses to take medication and/or food, when and how should carers decide that the patient's protestations should be ignored? It is clear in the case of Brenda that her family appeared to have influenced policy with regard to the administration of her medication. To what extent should the wishes of the family to keep a patient sedated

influence care? Who should be involved in the ongoing monitoring of the use of sedation - the patient, the family, carers and/or the doctor?

It is not the purpose of this study to address these questions from a legal perspective, or to engage in debate on current legislation, regarding the use of sedation as a form of restraint or indeed the use of physical or other forms of restraint. Rather, the aim has been to focus on the use of sedation and physical restraint *as an option in care management*, and the practical and ethical implications arising. Drawing on the practicalities of the case study above, the reasons *why* carers chose to manage Brenda in this way will be explored, including the implications of this approach. In addition, other possible options, and their implications for carers and patients, will also be examined. While the overall aim here has been to identify contextual and ethical elements influencing the delivery of care, the more specific intention is to bring to light possible connections between carers' understanding of dementia and the meeting of patients' needs. Consideration will also be given to the impact of certain practices on care delivery, including adherence to rigid ward routines and schedules.

Following the occurrence of the events described above, involving Brenda and her carers, it seemed important at the time to guard against interpreting the incident too narrowly by reflecting on it in isolation. It was felt that a somewhat broader canvas was needed against which to examine the questions arising from this incident, namely the context in which the incident occurred, including the time, place, atmosphere, the needs of other patients and their demands on staff. It also seemed important to get to know a little more about Brenda, and so several weeks of observations followed, in which carers' interactions with Brenda's specific patterns of behaviours and their ways of relating to her were noted and considered.

Taking the Uniqueness of the Patient into Account

Over a period of time it became evident that Brenda was indeed a very private sort of person, rather than simply withdrawn. Unlike other patients, she did not seem to have any desire to spend time with any other patient. She disliked crowds and would show her irritation at patronising conversation by refusing to respond when anybody attempted to engage her in conversation. In general Brenda was rarely rude or aggressive toward carers or patients, but objected to people invading her space. Her constant tears and whining noises while being bathed or toileted, for example, seemed to indicate possible feelings of desperation and sadness and/or the discomfort of physical pain.

Several things became evident from observation of the recurring series of events which occurred as carers interacted with Brenda over a period of many weeks. Firstly, it was never clear what caused Brenda to become agitated and to start shouting and whining. That is, it was never obvious, nor did carers appear to know if Brenda was actually in pain or whether her behaviour was reflecting feelings of sadness, fear, frustration and loneliness, given that she was known to be depressed. The administration of medication resulted in modifying her behaviour, making life less stressful for all concerned. Understandably, it also resulted in carers feeling good that they could do something for Brenda to relieve her 'pain'. Understandably it did however appear to reinforce the message that this approach worked every time, thus encouraging a tendency to stick with it as an effective management approach.

A significant problem with this approach, however, is its tendency to focus on the problem behaviour and not on the person as a whole. No consideration was given to the possible negative influence of the person's environment, including the possible irritation of the behaviour of others. Carers never ignored Brenda's distress, but it was not clear that they understood the reasons for it. For example, it is quite possible that Brenda might not have understood and, in fact, might never have consented to being washed, dressed or taken to the toilet. As a very private person, Brenda's reaction to these activities tended to suggest strongly that she found them embarrassing and unpleasant. Possibly adding to her discomfort was the fact that she frequently had different carers attending to her, including a young male carer from time to time.

It was also evident that Brenda did not like the high-level of activity, and especially all the background noises associated with mealtimes. As already indicated she did not like numerous people milling around her, nor did she find it easy to ignore or accept the poor eating habits of some patients. Brenda's response to the various activities and people in her environment tended to indicate that her previous lifestyle and preferences for interacting with people, coupled with the routine of Karibu Ward all combined to influence how she actually responded to her surroundings.

There seemed to be a number of factors that contributed to the perpetuating of this approach to care. At all times on the ward, care was taken to ensure that patients were not put at risk by the presence or use of potentially hazardous objects. For example, furnishings were kept to a minimum, and only essential cutlery such as spoons were used at mealtimes. As a result, the ward environment tended to look more institutionalised and less homely. However, why these measures were taken by carers and management, was understandable. While the concern of staff was for the safety of

patients, the issue at stake was how carers appeared to give high priority to 'risk-free care', without perhaps considering the need to balance it where possible with patient autonomy and individuality.

While the use of physical restraints was not a feature of care according to ward policy it could be argued that anything that prevents, or restricts, the normal bodily movement of a person could be described as a restraint. Holding Brenda's flailing arms down until she swallowed her medication, could be considered restraint but for the carers concerned it was simply a common-sense thing to do in the light of the alternative. If Brenda did not have her medication she became more disturbed and disruptive to other patients, so carers felt the only and most effective way of managing those situations was to prevent an escalation of events by administering medication as quickly as possible at the first sign of problems. The critical issue here was the fact that carers felt there were no other options available for managing the situation differently or more effectively. The following are some of the many reasons supporting and reinforcing this approach by carers.

Firstly, with regard to the restraining of Brenda both carers involved could be described as non-aggressive and matter-of-fact in approach. However, their abilities to interact with Brenda in a verbally reassuring way did not seem evident or adequate in the situation. *Secondly*, it might have been helpful to remove Brenda to a more private place at the outset. The layout and design of the ward did not allow for this, since there was no quiet room or private space in which carers could create a nurturing safe environment or atmosphere for a distressed patient. *Thirdly*, the staffing levels did not permit extended periods of one-to-one interactions with patients and, the option taken by the carers was an economical solution to the problem because it was a 'quick fix' that did not disrupt the routine of the ward or cause imbalance in workloads. *Fourthly* and finally, while accepting the fact that sensible use of sedative drugs might be advisable and necessary as an approach to care, there appeared to be no understanding or awareness of the potential benefits of other complementary approaches to care. For example, the ward did not provide access to regular or constructive activities such as aromatherapy, access to gardens and/or contact with pets - recognised stress reducing activities.

It would seem that the pattern of management of disruptive or disturbed patients such as Brenda was shaped by several factors including the routine servicing of patients. Carers seemed to take incidents more or less in their stride, as part of the ward routine. Assuming a custodial approach that restricts the autonomy of the patient,

was also a factor in their practice. In addition, no time was taken to explore the reason for patients' behaviour, which reinforced a focus on physical care. Carers seemed to be primarily task-oriented in approach and restricted by adherence to rigid routines. As indicated earlier, these approaches to care, coupled with staffing issues, restrictive and inadequate environmental design and features, as well as carers' lack of awareness of potentially beneficial alternative approaches, when combined, seemed to result in less than desirable or satisfactory outcomes, especially for the patients.

9.8 Conclusion

Contained in the examples discussed above, are elements of therapeutic relationships, which include the nurses' capacity to show genuine professional interest in the patients, with a willingness to share feelings and show sensitivity in an honest and open manner (Hughes 1999, p. 574). Citing the work of Marck on therapeutic reciprocity as a caring phenomenon, Mike Nolan argues that a genuine therapeutic relationship can only develop 'when there is a mutual exchange of feelings, thoughts and experiences that allow for the establishment of some form of shared meaning in the care-giving context' (Nolan 1996, p. 59).

With specific reference to carers' relating to older people, Nolan (1996, p. 62) goes on to say 'achieving the goal of therapeutic relationships requires that staff themselves: value older people; have the necessary skills to initiate and sustain relationships and have the appropriate environmental support'.

In summary, while carers on Karibu Ward were highly committed to meeting the physical care needs of patients, their practice fell short in some respects with regard to meeting patients' emotional and spiritual needs. In general the ward was poorly equipped, designed or maintained for supporting the emotional needs of patients. As noted in earlier chapters, there was no Quiet Room for relatives to gather to grieve in privacy or be together when a patient was approaching death. There appeared to be no provision made on the ward for religious services or rituals. There was no space available, no time set aside for rituals and no meaningful symbols evident in the environment.

Findings from observations would suggest that carers see their role as that of doing things for patients rather than assisting them to manage things as far as possible for themselves. While there were some situations in which carers could be said to extend their responsibilities beyond the specific job description, this tended to be the exception to the

rule, as in the example of the charge nurse choosing the golfing scene for the patient, in the hope of creating a positive link for her with the past.

While there were some examples of genuine bonds of friendship between carers and patients, this was not the norm, nor considered of any real significance to the delivery of care. In other words, the divide between patients and carers was distinct, with carers perceiving their role as that of caretaker rather than an enabler or friend. Carers and patients did not engage in any activities together other than interacting during the giving of treatment or when assisting with bathing or feeding for example. Reference was made in Chapter 7 to the fact that an occupational therapist was expected to be available on a part-time basis to work with staff but this did not occur throughout the duration of this study. There were no programs or activities for patients and no presence of staff on the ward, other than nursing staff to raise awareness regarding the possible benefits and necessity of extending patient care through supportive programs such as therapies and hobbies.

Social occasions such as Burns Night, and the Christmas Party, put considerable strain on carers due to the extra work involved for those on duty. For that reason planning and management of these occasions was often dependent upon the enthusiasm of one charge nurse in particular, while other carers contributed in a somewhat reluctant spirit. This was primarily an issue of limited resources to undertake extra work, but was also underpinned by some carers' belief that such occasions were of no significance to patients whom they considered 'out of touch with reality'.

Finally, it can be concluded that carers' perceptions of their role and that of the patients were defined by the traditional nursing model, namely in terms of nursing tasks and of patients being seen as the recipients of care. This approach tended to emphasise the illness aspect of the patient rather than their capabilities. The ward environment, in terms of design and appearance, lacked homelike elements, reinforcing a traditional hospital-like atmosphere including locked doors, the absence of personal belongings or personalised spaces. Overall, the findings of this chapter tend to reinforce perceptions of issues emerging from the last chapter, namely that carers were mainly committed to a custodial approach to care, and evidenced a significantly diminished understanding of and *ad hoc* practices with regard to the creation and maintenance of the therapeutic environment.

CHAPTER 10:

Quality Care & Carers' Job Satisfaction

10.1 Introduction

This chapter is concerned with how carers perceive their respective roles and some of the key factors underpinning their work experience on Karibu Ward. The chapter is concerned with factors, which significantly influence daily life on the ward and ultimately affect the delivery of patient care.

In particular the chapter will address:

- issues of job satisfaction and the implications for care delivery as identified by a number of pertinent surveys of nursing staff
- how nurse assistants perceive the role of caring from the point of view of the need for training, defining care and factors which motivate them as carers
- how qualified nurses perceive their role as team leaders, what they consider to be priorities in care and issues contributing to their job satisfaction
- issues relating to the inter-relationships of staff and factors which influence teamwork and the work environment
- other factors which appear to significantly influence care assistants' attitudes to their role and ways of functioning
- ways in which inadequate care practices are perpetuated, in particular how handovers are managed and critical information is shared
- how Karibu Ward is perceived as the 'Cinderella' service of the hospital, the implications of this for nursing staff and its flow-on effect on care delivery

10.2 Job Satisfaction and Quality Care

The literature indicates that some carers see the wide range of challenges that are associated with their task as an opportunity to play a very positive role in the life of a person with dementia (Thompson 1995, p. 110). However over the past decade, a significant number of surveys have focussed on staff attitudes and job satisfaction in caring for dementing elderly people (Philip et al 1991; Alfredson & Annerstedt 1994; Gilloran et al 1994; Giloran et al 1995), raising a variety of issues about job satisfaction and the

implications for the delivery of quality care. One study by Gilloran et al (1995) examined in particular the differences in work satisfaction between staff nurses and other grades of nursing staff in psychogeriatric wards, in National Health Service hospitals in Scotland. Their results indicated that there were significant differences in terms of job satisfaction and perceptions of ward morale, between staff nurses and other nursing staff.

In relation to individual job satisfaction, staff nurses were the least satisfied with what they were getting from their work. They also rated the level of morale lower than other staff. Findings from this study demonstrate that factors relating directly to the organisational structure and the way in which management functions influence the overall levels of job satisfaction experienced by nurses. It is, however, the flow-on effect that is perhaps the more critical issue here, that is, the relationship between job satisfaction and the quality of care delivery. The Gilloran et al (1993) study claimed that there was a strong association between the levels of job satisfaction experienced by nurses and the quality of care delivered to individuals in psychogeriatric wards.

Their results support findings of an earlier study by Philp et al (1991), which found that staff in psychogeriatric wards had significantly lower job satisfaction compared to nurses in other speciality areas. However, there appears to be no real agreement between them on the causes of these findings. A number of other studies have identified several variables such as leadership styles, training opportunities and improved working conditions as factors that appear to contribute to levels of job satisfaction. Alfredson & Annerstedt's study (1994) concentrated on personal and work-related effects on staff, as part of a larger study, evaluating group living (GL) care for demented elderly people compared with traditional institutional (TI) care. A staff-training program was implemented, including relevant gerontological knowledge, support and supervision. Outcomes revealed increased knowledge and new emotional and social attitudes. In addition there was evidence of higher competence and professional conduct toward patients as well as increased motivation, job satisfaction and quality of work in (GL) care staff but not for staff in (TI) settings.

Another study by Duxbury (1984) identified a link between job satisfaction and the degree to which staff members felt head nurses took account of their needs. A study by Humphris & Turner (1989) found a link between improved working conditions, following the relocation of staff to new premises, and job satisfaction. Astrom et al (1991) reported that burn-out in nurses correlated with less positive attitudes toward dementia patients and low empathy levels. This small sample of studies, based primarily on staff views, appear to indicate that job satisfaction does have an impact on quality of care. From the studies cited above it would appear that variables such as leadership styles, training and development

opportunities, and working conditions do impact on the degree to which staff members feel satisfied with their jobs. These studies also help to sustain the argument that there is a link between job satisfaction and the quality of care delivered.

This Chapter is therefore concerned with the exploration of several variables identified above — such as leadership styles, training opportunities and levels of job satisfaction — for the purpose of considering their possible impact on how carers approach the task of caring and ultimately on the quality of care delivered. Other factors and influences that will be considered are the possible links between attitudes of low morale apparent among some staff members and perceptions of Karibu Ward. Attention will initially be directed to carers' perceptions of their roles and the issue of training in particular.

10.3 Carers' Perspectives

10.3.1 Nurse Assistants

Nurse assistants make up almost 75% of the overall staff complement and hold firmly to the view that only basic nursing skills are required to undertake the majority of the tasks defining patient care. Getting patients up, dressed, fed, washed and toileted is the 'real' work of patient care, according to nurse assistants. Because they are primarily the ones who undertake these tasks, they therefore see themselves in effect as the backbone of care delivery on a day-to-day basis. They also hold the view that these required nursing skills can be learned 'on the job'. When asked in interviews if they felt training in dementia care was necessary in order to ensure adequate care for patients, 50% of nurse assistants — mainly the older members — were adamant that no training in dementia care was necessary. Some assistants elaborated by explaining that they had no formal training, still did not understand dementia, but believed they did their job quite well. These views were expressed as follows: *'it's practical care they (the patients) need, you learn that on the job'* and *'it's a hands-on sort of job, you learn it as the weeks go by'*.

Many of the other 50% of care assistants who were relatively young or new to the ward, agreed with the sentiments expressed by their older colleagues regarding the nature of care, but were also of the opinion that some formal training in dementia care could be helpful. This position was reflected in responses such as *'it's important to understand why the patients act the way they do, e g, violent behaviour'*, *'it would be*

helpful to understand the whole process of dementia in order to deal with patients more respectfully', 'better understanding means better care'.

It is of interest to note that despite the fact that junior members of staff had been orientated to their role and introduced to 'shared meaning' (Harding & Palfrey 1997, p. 12), by their more senior colleagues, they did express some independent judgements regarding care delivery. More specifically, they reflected independent views – contrary to mainstream thinking on the ward – regarding the need to understand dementia as a critical aspect of nursing care and what it means to be a professional carer.

Some nurse assistants had undertaken an orientation programme on the ward under the guidance of trained nurses. This programme was intended for new staff, with no previous experience of caring for older people with dementia. It entailed following a set of guidelines such as health and safety responsibilities and lifting techniques, which when learned were ticked off by the trained nurse over a six-week period as the new carer gained experience, know-how and the necessary skills to become a fully-fledged team member. If, however, the new carer came from another ward - especially one of the other three wards within the complex - no orientation was considered necessary. It was assumed that they were coming with experience and would learn how to do things specific to Karibu Ward as they went along, and were expected to ask questions if unsure how to proceed.

Throughout the period of data collection it became evident that the majority of nurse assistants held a very entrenched position regarding the lack of need for formal training. Six nurse assistants had worked on the ward between 3-4 years and two for less than a year, while the remaining assistants had been there well over five years – some senior members of staff having worked with elderly people in the hospital between 10-20 years. It was many of the latter who were particularly adamant that formal training was not necessary to do a good job, and that the ward would actually function quite well without qualified nurses. These carers appeared to be particularly confident in their work, based primarily on many years' experience and were also very committed to 'getting the job done' by staying task-focussed. It was obvious that the more experienced nurse assistants tended to be the judges of their own work, taking pride in a job well done and not dependent upon feed-back on their work from team leaders (Astrom et al 1991, p. 66). These views were underpinned by the things assistants understood to be most important in patient care. Interview responses

indicated – as discussed in Chapter 8 – that good physical care and patient comfort were priorities, along with patient safety.

Other aspects of care, such as respecting the dignity of the person and showing kindness, were considered to be very important – all of which nurse assistants felt they did automatically without the guidance of training. When asked if they chose to work on this ward, five nurse assistants indicated that they wanted to work with elderly people and were happy to do so on this or any of the other three wards in the complex which catered for the needs of elderly people living with dementia. Five additional assistants were sent to Karibu following the closure of other wards in the hospital. As for the remaining nurse assistants – some had been unemployed for some time and were willing to take any work available, while others needed part- time work and the time schedules available on the ward did not interfere with other personal or family commitments.

While the factors motivating carers were wide ranging, there appeared to be no obvious negative outcomes in terms of patient care. This appeared to be so because the ward was using a standard staffing pattern, in which carers were assigned specific tasks such as bathing and toileting, rather than having responsibility for specific patients. In addition, as discussed in Chapter 8, staff's over-riding concern with catering to the physical needs of patients ensured that their basic needs and comfort were attended to as a matter of course. In other words, carers viewed their role as completing a series of tasks rather than giving priority to building a relationship with patients as a basis for care and/or understanding their behaviours.

Given that patients who came to the ward did not improve in health, but rather deteriorated over time, remaining on the ward until they died, it seemed important to find out how carers felt about their work environment. Responses to these questions were very varied. While recognising the fact that some aspects of working on the ward could be difficult and trying from time to time, approximately six assistants reflected positive attitudes and warm sentiments toward the patients in their care. These were expressed in a variety of ways such as:

- *'it's a privilege to care for these ladies'*
- *'we become fond of the patients and it can be very upsetting when somebody dies, especially if they have been here for a long time'*
- *'I hope when I go home in the evening that I have done a good job for these people in their last days or years of life'.*

The attitudes reflected here seemed neither benevolent nor over-stated but rather respectful and indicative of job satisfaction. However, for the majority of assistants, the experience seemed to be less rewarding and somewhat negative. Some expressed quite directly that they did not have much job satisfaction, while others made reference to the depressing nature of the work, the monotony of ward life and the mundane aspects of many tasks. Four younger carers, in particular, felt there was nothing new to learn and felt they did not have a future on the ward, in terms of career development or opportunities. Overall these responses conveyed a feeling of little job satisfaction and no evidence or hope of changes in the ward environment for the foreseeable future.

10.3.2 Nurses

Compared with nurse assistants, nurses generally had fewer years of experience on the ward, ranging from 1-5 years. One nurse had been there less than a year while five others had been on the ward for 3-5 years. Given that only one nurse worked on each shift and that they did not meet or spend time together except for the purpose of handovers, one therefore did not get a sense of them functioning as a group, unlike the nurse assistants. The nurses could best be described as individuals in terms of how they functioned in their roles. The main distinguishing feature of the trained staff was their role of team leaders, which involved writing patient reports, giving and receiving handovers, administering medication and having overall responsibility for the welfare of patients.

Only two of the six nurses had actually chosen to work on Karibu Ward, the other four, like many of the nurse assistants were '*sent to the ward*' because other wards had closed down. When asked what they thought were important factors in patient care, nurses gave priority to:

- high quality staff
- good equipment
- patient comfort
- a homely environment
- ensuring the privacy and dignity of patients.

It was perhaps predictable that nurses listed the need for high quality staff as their top priority, since as team leaders, securing the required number of competent staff appeared to be an ever present and ongoing issue for them. Since overall responsibility for patient care rests with the nurse as team leader and qualified

professional, they often felt severely disadvantaged when they had to rely upon inexperienced nurse assistants and transient staff - especially bank and/or agency staff unfamiliar with the ward and the patients.

Nurses considered that adherence to routine approaches to care facilitated 'the quick and effective utilisation of transient staff... to be able to recognise quickly, and with minimum instruction, the care needs of patients on the ward' (Procter 1989, p. 187). This process tended to reinforce the need to routinise care practices while perpetuating a culture of dependency on transient staff. This was a contentious issue for team leaders, due to staff having sometimes only limited skills and no experience of the ward or patients. It was also an issue for other regular ward staff, due to their experience of having to take more than what they considered to be their fair share of the workload, when working alongside bank or agency staff.

On the issue of the need for formal training as a basis for patient care, four of the six qualified nurses felt it was important to understand the physical and psychological needs of patients, including their behaviour and the nature of their illness. The remaining two nurses felt learning from experience on the job was adequate – they had worked with elderly people on other wards in the hospital. While over half the nurses felt it was important to understand the physical and psychological needs of patients, these comments seemed primarily to refer to understanding the patients as elderly people with a much lesser emphasis on the issue of dementia.

In practical terms, qualified nurses undertook the same tasks as nurse assistants but in addition dispensed medication and took responsibility for the overall functioning of the ward and the care of patients. While nurse assistants viewed patient care in terms of a series of practical tasks, nurses seemed to perceive patients' problems in more complex terms. For example, nurses had responsibility for the ongoing observation and assessment of patients' wellbeing. This included the monitoring of treatment of pressure sores, sleep disturbance, problems with constipation and complications associated with falls. The monitoring and management of these problems often required very refined nursing skills — given the patients' reduced ability to understand or follow instructions or advice. This was a point sometimes overlooked by nurse assistants.

Given that medical ward rounds were not conducted, the ongoing assessment or monitoring of patients, (which would more usually include a member of the medical staff), was undertaken by the nurse during the drug round. This was the time when nurses looked to see how patients were doing, a task sometimes referred to as 'doing

the medical' in traditional nursing settings. Through the use of the drug round to undertake patient assessment – in a sense on behalf of medical staff – nurses conveyed a message regarding the importance of this activity, which could not be undertaken by nurse assistants and by implication reinforced their position of authority. As team leaders, nurses set the tone and significantly influenced the atmosphere on each shift. However, their leadership styles varied greatly, as did the responses of nurse assistants to their leadership as illustrated in the following examples.

10.4 Leadership Styles and Staff Relations

As already discussed, carers generally did not welcome any changes to or disruption of daily schedules. While this attitude sometimes proved problematic for reasons already explored, at other times, and in different situations, adherence to familiar routine practices ensured that at least patients' needs were met, despite tensions and difficulties. For example, it became evident even during the initial weeks of observing ward routines and activities that the atmosphere on the ward would sometimes change quite significantly, even from one shift to the next. From further observations it seemed that certain situations such as managing several demanding and disruptive patients at the same time, or having to change several severely incontinent patients numerous times on a shift, caused carers some distress and dismay. However, when asked to comment on these observations, the majority of nurse assistants were very forthcoming about the obvious change in atmosphere but identified strained team relations as the key source of the change, rather than work demands. A second factor was identified as a cause of bad feeling and articulated by one carer as *'people slacking on the job'*. This also included claims that use of bank or agency staff unfamiliar with the ward routines and/or patients, had a flow-on effect of a greater workload for regular ward staff.

Different leadership styles seemed to be key factors in strained team relations and were identified by carers as a key source of negatively-charged atmospheres. Team leaders are trained nurses, and, compared with nurse assistants, nurses often had fewer years of experience on the ward, ranging from 1-5 years. One nurse had been on the ward less than a year; the other 5 nurses had been there 3-5 years. Given that only one nurse worked on each shift and that they rarely met or spent time together, except when giving and receiving handovers, one did not get a sense of them as a group, unlike the nurse assistants. The

nurses, then, could best be described as individuals in terms of how they functioned in their role.

However, as team leaders, nurses were responsible for report writing, giving and receiving handovers and administering medications, as well as having overall responsibility for the welfare of patients. Given that ward rounds were not conducted, the ongoing assessment or monitoring of patients, which would usually include a member of the medical staff, was undertaken by the nurse during the drug round. This was the time when nurses sought to 'look and see' how patients were, a task which was sometimes referred to as doing the 'medical'. Through the use of the drug round to undertake patient assessment - in a sense on behalf of medical staff - nurses conveyed a message regarding the importance of this activity, which could not be undertaken by nurse assistants and by implication reinforced a hierarchy of power. As team leaders, nurses set the tone and significantly influenced the atmosphere on each shift. As might be expected, their leadership styles varied greatly, as did the responses of nurse assistants.

The majority of carers were smokers and smoking in the staff room - which was a rather confined space - was a common practice during coffee or meal breaks, handovers and at other times. One nurse objected to smoking and as a result refused to spend time in the staff room with other team members. While it was obviously her right to choose not to be in a smoke-filled room, it meant she also missed out on interacting informally with others including the general fun and banter that makes up staff relations on an ongoing basis. This in effect meant that if another carer wished to speak with her at these times they could only do so in the more formal setting of the staff office. This divisiveness carried over into general interactions between leader and other carers impacting on the management of workloads. The nurse assistants felt this particular leader did little to nurture good team relations, and in effect they believed she tended to reject the 'smoker as well as the smoking'.

In practical terms staff appeared to respond in a variety of ways to her leadership. For example, one older and very experienced nurse assistant - who was not a smoker either - tended to take a very practical view of things and believed in just getting on with the job without 'interference' from team leaders. She only seemed to relate to the particular team leader in question on critical issues relating to patient care, while other nurse assistants tended to adopt a work-to-rule attitude toward the leader. The work always got done but often in a grudging fashion rather than with a generous spirit, under the leadership of this particular nurse. There tended to be a kind of cat-and-mouse atmosphere among staff when this particular person was leading a shift.

Another leader evoked different responses in the staff. Even though she too was not a smoker, she did join the staff in the staff room for breaks. The staff felt she was very fair with them and also worked hard herself, sometimes putting in extra hours and effort, especially in preparation for special events for patients. While she tended regularly to remind nurse assistants of the importance of formal training, which they did not believe or wish to hear, she mostly had their support. She seemed accessible and it was also very evident on occasions that nurse assistants did not feel as intimidated by her as they did by the leader previously discussed.

There did not appear to be a forum for exploring issues that arose from time to time among staff. Tensions were usually evident and expressed in the staff-room, where individuals would express their anger or dissatisfaction about work issues. There did not seem to be a culture of dealing with issues. Rather, conflicting views tended to be expressed following which individuals would simply leave the staff room and direct their energy and attention to the task of caring for patients. Creating distance and avoiding unnecessary contact with 'opponents' appeared to reduce the conflict but did not resolve it in a more constructive way. Avoidance behaviour was further facilitated or reinforced by individuals having rostered days off — often 6 days consecutively — which allowed for a change in personnel and a dissipation of tension without resolving issues in the interests of better working relations.

When asked how they felt about working on Karibu Ward in the light of the fact that patients did not get better and in all cases remained there until they died, nurses seemed less articulate and less responsive than nurse assistants. With the exception of one nurse who felt they should try to provide a variety of activities to make life as interesting as possible for patients, nurses in general felt patient needs could be adequately met through a maintenance approach, which was primarily concerned with their comfort and safety. Their views were expressed as follows:

- *'we do what we can for patients'*
- *'we do things for them to the best of our ability''*
- *'keeping them (the patients) comfortable is the most important thing'.*

These rather passive attitudes towards patient care tended to reflect perceptions of older people as clinically uninteresting and for whom little could be done. In other words it was suggested that these patients could not be cured, and therefore maintenance of their condition was the aim of carers, which did not necessarily require very specific skills or knowledge. This view, which supported the understanding of nurse assistants, implicitly called into question the role of nurses in this setting.

10.5 Other Factors Influencing Carer Assistants' Attitudes to their Role

Based on observations and conversations with carers, several points seemed to underpin carers' attitudes and relationships with each other. For example, some carers had previously been unemployed and were willing to accept any work available. This is not intended to suggest that financial income was their only motivation in caring for patients, but it does recognise the fact that some carers felt trapped by limited job options and therefore had to 'stick with it because it was a job'. For these carers it clearly was difficult to stay motivated toward work that they experienced as menial and monotonous and not really of their choosing.

The drudgery of ward life was also influenced by the apparent lack of commitment to the ongoing education or training of staff. Training was perceived as staff acquiring or developing the necessary practical skills to facilitate the delivery of good practical care to patients. Throughout the duration of the study it was observed that carers did not attend any in-service education and training — with the exception of health and safety demonstrations as legally required of hospital staff. The negative attitudes of some nurse assistants to training, was a matter of concern for many of the qualified nurses as team leaders. The fact that some assistants expressed no interest in training or simply refused to undertake ongoing training caused some dismay among nurses. It was a major concern according to one nurse, that *'the hospital lacked interest in and apparent conviction of the significance of training'*, and that *'there was no culture of staff pursuing further training in the hospital'*.

As is the practice in other care centres, the overlap of shifts between 1.30 - 3.00 pm each day did allow time for training and staff meetings as well as the opportunity for one-to-one activities and individual time with patients. Staff meetings were held on the ward during this time, enabling the majority of carers to attend but there was no evidence of any structured training or workshops for staff during this time. This would suggest that the issue was not so much a lack of time for training but rather a matter of perceiving it as a low priority.

Finally, the evidence from interactions with nurse assistants suggest that older members were pragmatic about life on the ward and assumed an attitude of *'getting on with the job'* or *'sticking with it'*, underpinned by an awareness that they might have difficulty getting other jobs should they decide to leave. Younger assistants seemed to feel the repetitive and mundane nature of the work was not only unappealing but also restrictive in terms of developing skills in care delivery on the ward. The fact that they felt opportunities

to learn new things were limited, reinforced the view prevalent on the ward that aged care is professionally restricting and generally unrewarding.

Despite some differences in their perspectives of ward life, job satisfaction and years of experience, nurse assistants did tend to band together as a group in the work environment. Their solidarity seemed to be based on a number of points discussed above, as well as – and perhaps somewhat oddly – on their identity as 'untrained' carers. They usually referred to themselves as untrained, as a way of being distinguished from qualified nurses. It was also noticeable in conversations that instead of indicating that they chose or wished to be a nurse assistant they would rather tend to say *'I don't want to be a nurse'* and *'I'm not interested in nursing'*. However, these statements often seemed to betray feelings of inadequacy rather than lack of interest in being a nurse. As a group, nurse assistants did not draw their confidence from formal training, but from the knowledge that the ward would not function without them. They seemed secure in the belief that their practical skills and experience formed the backbone of the day-to-day patient care. These entrenched positions seemed to remain unchallenged for a variety of reasons, including strict adherence to ward schedules and on-the-job training which tended to reinforce routine practices and understandings of care delivery. In this way inadequate care practices could be perpetuated by default or unintentionally.

10.6 Perpetuating Inadequate Care Practices

It has been standard practice in nursing that handovers take place at the change of each shift and are conducted by the nurse in charge of the shift. The process, which is usually treated with a certain formality, is based on nursing records and up-to-date file notes on each patient. The more common practice has been to give a report on each patient, but not necessarily to dedicate an equal amount of time to each patient, irrespective of need. The level of formality, in terms of written records; the degree of detailed information on patients and the time dedicated to the overall task seemed to depend upon a number of factors.

On Karibu Ward handovers from the night shift were usually brief, containing only general reference to the majority of patients, with more specific observations about individuals who for whatever reason were considered disturbed or troublesome during the night. This seemed both logical and understandable. The enrolled nurse, giving the handover from the night shift, usually appeared somewhat lacking in confidence when discussing the condition of patients at any length with her counterpart on the morning shift, who was a

qualified nurse with many years' experience. In general junior staff members seemed to feel less competent and confident in the presence of their senior and more experienced colleagues.

There were however many other factors, such as time constraints, which seemed to influence the giving and receiving of reports. The person giving the report invariably seemed eager to get off duty as quickly as possible, after a long and weary shift. The person receiving the report seemed equally concerned to get the necessary details about patients passed on to her team without delay. The routinisation of handovers seemed to determine what was ruled in and/or out of reporting; who was involved; how patients were discussed and workloads allocated. Many of these well-established practices potentially undermined the delivery of quality nursing care for patients, by reducing the task of caring to a minimalist approach, which also diminished carer job satisfaction.

For example in a scenario relating to the admission of 'Mrs Kirk' to the ward, discussed in Chapter 8, little information was passed on to carers by the charge nurse at the handover. In addition there seemed to be a discrepancy between the information shared and carers' actual experience of the patient on admission. Even if more information had been available on Mrs Kirk, the time constraints on handovers did not permit the sharing of detailed information, however necessary it might have been. The sharing of essential information was obviously dependent upon what understanding the charge nurse had in the first place from the admission of the patient to the ward. Much also depended upon what the charge nurse deemed important and necessary for other carers to know and understand as a basis of care. Nurse assistants rarely participated in handovers or asked questions regarding specific aspects of care delivery, accepting instead directions from the team leader.

Handover meetings *on the ward* were virtually non-existent in the sense that there was little staff participation, which had several serious if not potentially detrimental outcomes for patient care. As in the case of Mrs Kirk, nobody on the care team learned anything about her as a person, apart from the fact that she had a frail husband. If a carer wished to get to know a patient, they had to rely upon what they experienced individually, directly and personally with the patient. Awareness of personal details of the patient could make a positive constructive contribution to the overall care of the patient, however, it could also be very subjective and misguided, depending upon the carers' interest, experience and goodwill. Much seemed to depend on the motivation, personal qualities and understanding of care which individual carers brought to the situation. Given that nurse assistants relied almost entirely on induction and on-the-job training, the scope for staff developing insight into and

awareness of patients' needs, or cultivating communication skills seemed haphazard for the most part.

This was particularly so, since no time was set aside in handovers for the training/teaching of new or junior staff. The view seemed to be that there was little to teach Karibu Ward — unlike a medical or surgical ward, where patients and their needs change significantly from day to day or even within a matter of hours. However, the fact that no time was devoted to ward instruction and teaching — formal and informal — meant that new staff members depended on learning ways of caring from the established routines set by other staff. There is much to recommend in a learning-on-the-job approach, provided that methods of practice and carers' approaches to care are regularly monitored to ensure acceptable standards of practice are upheld. On Karibu Ward, the monitoring of practices such as how best to lift a patient in order to avoid self-injury or patient discomfort or strain, appeared to be haphazard and dependent upon the energy and interests of individual charge nurses in particular.

The particular issue on the Karibu Ward was the relationship between the way handovers were conducted and how carers were kept informed regarding the wellbeing and progress of patients at any given time. This became a more critical issue in light of the fact that nurse assistants did not write or read patients' reports or care plans. This raised the question of how nurse assistants got to know patients or stayed abreast of their changing needs and/or care requirements. Information was passed on by word of mouth from charge nurse to other carers. While this seemed to be the accepted way of doing things, the adequacy of this approach was taken for granted without any question of its impact on patients and care practice. The manner in which handovers were conducted, as outlined above, suggests many opportunities were lost, particularly in relation to the exchange of views on patient care and the overall understanding and care of individual patients.

The current practice of handovers, which consisted of an exchange of information between two qualified nurses — or an enrolled nurse as indicated above — tended to reinforce a focus on the medical or nursing aspects of patient care, with no apparent consideration for the psycho-social needs of the patient. Current practice seemed to reinforce the medical model despite its recognised limitations in terms of emphasis on disease and illness, rather than on the patient's needs as a whole person. The psychosocial needs of patients on the ward were not totally ignored or neglected. My observations suggest that these aspects of patients' needs were usually met by default and were not considered of equal importance to clinical or medical needs.

10.7 Karibu Ward Perceived as the Cinderella of the Hospital Service.

While nurse assistants seemed to be very aware of their position in relation to the qualified nurses on the ward, the latter on the other hand were more concerned with their professional standing in relation to nursing staff on other wards in the hospital. This was frequently evident in conversations with nurses, which revolved around the issue of how Karibu Ward and their role in providing nursing care was perceived in the wider hospital. Nurses made reference to the fact that Karibu Ward was perceived to be the 'Cinderella' of the hospital, in the same way that care of the aged and especially patients with dementia were spoken of as 'the Cinderella service of the National Health Service'. On further exploration it became evident that several factors had contributed to and continued to sustain this image of being a neglected area of the hospital.

For example, it was the belief of the nurses that other areas of the hospital, such as the new forensic unit, wards dedicated to the care of young anorexic patients, drug and alcohol abusers, and those who had attempted suicide, received greater attention, funding and research investment than Karibu Ward and/or the other three aged care wards in the same complex. This was seen to be directly connected with difficulty in maintaining staffing levels on the respective wards. Nurses were of the opinion that the patients on Karibu Ward were totally dependent on staff for all their needs, and that the nature of the work did not require highly trained nurses. However, they believed that this did call for an increase in the number of staff, given the labour-intensive nature of the work. The observations of the nurses – all of whom had worked on other wards – was that the other areas mentioned above, where nursing was of a therapeutic nature, appeared to have an abundance of staff compared with Karibu Ward.

In addition, attention was drawn to the poor condition of equipment such as patients' chairs, hoists and essential domestic appliances, as indicators of the lack of funds available to Karibu Ward. These observations were made individually by the nurses rather than by the nurses as a group. Some were more articulate in this regard than others, and while all of the points were raised by three nurses in particular, all of the points were also raised on many occasions in general conversations.

The Cinderella image of Karibu Ward as reflected in the attitudes and thinking of its nurses, for whom this tended to reinforce the image of dementia and indeed geriatric medicine as a 'backwater' of medical and nursing practice (Redfern & Ross 1999, p. 526), was discussed in Chapter 3. The qualified nurses on Karibu Ward seemed to be aware of the fact that historically, aged care was seen as more suited to unqualified staff with low ability

and limited ambition. In other words the nurses' concerns regarding the image of the ward, tended to suggest that change was slow despite considerable development in recent years and significant commitment to research into aged health care problems. Kitwood's 'new culture of care' was based on the belief that staff must be supported if they are to give person-centred care to patients. Kitwood's approach to care stresses the importance of meeting the personal and psychological needs of staff as well as patients as neglect of their needs has a flow-on effect on standards of care for patients. Conversations around the 'Cinderella' image of the ward always seemed to convey a feeling of low morale among staff as well as a sense of being at 'the bottom of the heap' in terms of professional standing. The question of professional standing was of considerable concern to nurses, in particular, believing that the longer they stayed on Karibu Ward, the more damaging it was thought likely to be in terms of any future career moves they might make.

10.8 Conclusion

Given that Karibu Ward was part of a very large hospital - having major teaching and research facilities, as well as being a primary training base for medical, nursing and paramedical staff - it did not seem to benefit from the availability of a wide range of professional skills or sophisticated physical treatment facilities. In fact the ward was quite traditional, particularly in design and staffing patterns, which impacted on how care was delivered as well as contributing in part to how carers felt about what they did and how they prioritised elements of care. Despite the potential advantage, then, of the geographical positioning of Karibu Ward in relation to other facilities in the hospital, the findings suggest that it may in fact have been a disadvantage.

This perception was due to the prevailing perceptions of the utter helplessness of patients on Karibu Ward and its image as 'the last stop' for them. These views, which were held and perpetuated by carers inside and outside the ward, created feelings of apathy and served as a reminder that aspects of aged or geriatric care may still be perceived as having a low priority in the broader scheme of health care, and that this area is less important from a nursing care perspective.

Considering the issue of staffing on the ward it became evident that senior nurse assistants and some qualified nurses were very experienced carers, but lacked openness to the possible value of ongoing training and new approaches to care. This is one of a number of factors that contributed to the maintenance of a routine approach to care, considered

earlier as the routine geriatric style. This approach is underpinned by the belief that elderly patients are like children, who are physically dependent and need assistance with the physical activities of daily living, with little account being taken of their psychosocial needs. The organisation of work by carers according to the routine geriatric style was primarily geared to getting the job done in an orderly manner and with maximum economy of human resources, which was consistent with how patients' needs were perceived. This approach ensured the adequate and consistent care of the physical needs of patients on the ward. However, it was limited and inadequate against the background of more recent development in the understanding of dementia and the needs of people living with the disease, according to theorists Tom Kitwood, Mary Marshall and others.

As highlighted earlier, some junior nurse carers did feel the need to understand more about how dementia affects patients. Their view was that this was desirable to understand better problem behaviour in patients. However, this was never seriously considered – given the fact that the suggestion came from young inexperienced carers, who were junior members of staff, in a profession that is strongly hierarchical. Finally, the issue of how carers felt about working with patients on Karibu Ward, and the 'Cinderella image' of the ward impacted on staff motivation. While nurse assistants tended to define their role by comparing it with the tasks undertaken by qualified nurses, the latter on the other hand tended to define the value of their role and their professional status in comparison with the roles of qualified nurses on other wards throughout the hospital. Reflecting on these comparisons seemed to undermine staff morale, causing qualified staff to consider seriously how long they felt it would be wise to stay working on the ward in the interests of their professional development and future career opportunities.

CHAPTER 11:

Summary of Study

The purpose of this study was to explore the contextual influences and any ethical issues inherent in the process of caring for people with dementia. In particular the study was concerned with how carers' management of these factors contributed in practice to the quality of care delivered. The study was motivated by the desire to bring greater clarity to the nature of the practical tasks carers had to manage on a daily basis and any possible implications for service improvement, staff development and/or other aspects of care delivery.

From a list of 53 registered nursing homes/hospitals provided by *Age Concern Scotland* in conjunction with *Lothian Health Board*, seven care settings were selected and visited as an initial step in choosing an appropriate site for the study. During these visits it became evident that the dependency levels of residents and the extent of their disruptive behaviour were significant difficulties inherent in the nursing care of patients with severe dementia as perceived by staff. The insights gained in this process influenced the decision to focus the study on patients who were least able to cater for their own needs and whose behaviour was considered to present problems for their nursing care. It was felt that study of the management of such patients would prove more illuminating of the challenges faced by carers than a study of care settings where patients were relatively autonomous and where disruptive behaviour did not pose a challenge to staff and/or other patients.

Initially it was felt that a comparative study based on the selection of two care settings would be preferable for the purpose of meeting the aims of the study. However, it became evident during the selection process, including the visits to the care settings, that a comparative approach would present practical and logistical difficulties as outlined in Chapter 4. It was therefore decided to base the study on Karibu ward given that it catered for the needs of a significantly larger number (20) of patients with severe dementia.

The findings of this study are based on the work and experiences of twenty-four carers on Karibu Ward who were willing to be observed in the process of care delivery. They also agreed to participate in semi-structured interviews and on numerous occasions enhanced the quality of the data gathered through informal conversations and helpful comments. Data also emerged from unplanned activities and opportunities associated with the care of patients and day-to-day life on the ward including for example interactions between patients and visitors.

As an exploratory study based on a grounded-theory approach the following five particular aspects of care or themes were identified following several weeks of observations of carers at work on Karibu Ward:

- routine
- emphasis on physical care
- communication
- environmental issues
- management of people with difficult behaviour

These themes formed the basis of further data collection providing a more in-depth focus on how care was delivered, the nature of issues arising of a practical and/or ethical nature and their implications for carers and patients. In addition to the five themes identified, other pertinent information was gathered regarding how carers experienced their respective roles, their sense of job satisfaction and factors contributing to staff morale. Some of the findings of the study reflect insights gained into specific themes, while others are of a more general nature arising from the relationship between and/or the overlapping of a number of themes as outlined below.

11.1 Summary of Findings

11.1.1 Routinised Care Issues

From the outset and throughout the period of data collection one of the key features underpinning care delivery was a composite of specific daily and weekly scheduled tasks. The tasks were clearly defined and performed within set time frames as outlined in the discussion on the daily rhythm of ward life in Chapter 6. It was argued that the rationale for this approach to care seemed to have its roots in well established traditional nursing practices, the skills and knowledge of which were foundational to registered nurse training. All team leaders on morning and afternoon shifts were registered nurses, primarily responsible for all aspects of nursing care.

My observations were that care delivery seemed to be based on prescribed methods of practice and standardised routines with which patients were expected to comply, which concurs with Pearson et al's (1997, p. 27) discussion on nursing models for practice as discussed in Chapter 6. It would seem too harsh to conclude that this approach to care based on an expectation of patient compliance to set routines and the rules and regulations of care practices was dehumanising for them. However,

based on data explored in Chapters 6 and 7 in particular it was concluded that carers did not seem to facilitate patient choices in matters relating to preferences in food, clothing and bed-time for example.

This approach did therefore negate patient autonomy to some degree and unintentionally it would seem or by default discourage patients from exercising choice and/or articulating their preferences, which are at the core of personal identity and individuality according to Kitwood's theory of a person-centred approach to care. (1997, p. 136) The underlying assumption of this approach seemed to be that the carers knew what was best for the patients who needed to be protected from making poor judgments. This understanding seemed reflective of carers who 'were educated in and still practise in a system (and in a manner) that is paternalistic and controlling' (Rader & Tornquist 1995, p. 12) which can undermine an ethical approach with regard to upholding patient autonomy and ensuring that due consideration is given to patients' wishes when and where appropriate.

Despite carers' obvious commitment to meeting the needs of patients certain practices seemed reflective of a warehousing approach to care – discussed in Chapters 6 and 8 – and therefore lacking in sensitivity. For example, toileting rounds were scheduled at regular intervals throughout each day irrespective of individual patients' needs. In the same way the bathing of patients was managed in a regimented manner, often lacking in privacy, a consequence of the need to toilet/bath large numbers of incapacitated people in a communal space within a defined time-frame (Hughes & Wilkin 1987, p. 414). Not only did this approach make public an otherwise personal and private activity but the inability of patients to object to the practice and/or express their embarrassment seemed to be overlooked by carers. As a result the practice was perpetuated as a matter of course.

It is also important to note that toileting patients according to need – as was the practice in some of the nursing homes involved in the pilot for this study – was considered helpful in reducing incontinence among them. There was no indication that carers on Karibu Ward were aware of the possible benefits or practice elsewhere of toileting patients according to need. It is therefore concluded that many aspects of care delivery practices on Karibu ward were tightly scheduled and undertaken as group tasks which often lacked consideration of individual patients' privacy and needs.

It is recognised however, that not all aspects of routinised care are potentially damaging or unhelpful to patients from the point of view of exercising control over their own lives as much as is possible for them. Taking into account the argument in

support of the significant benefits of routine and order for patients with dementia as established by Norman (1999, p. 556) in his discussion on nursing older people and Cormack (1985, p. 283) with respect to reality orientation, the following observation is made. It was evident that carers adhered strictly and it could be claimed somewhat rigidly to routines. However, it cannot therefore be concluded that this approach provided patients with a sense of predictability of events leading to a greater sense of control over their lives (Norman 1999, p. 556). Key to this argument is an understanding of what is meant by routine. For Kitwood and Marshall as established in Chapter 6 the person with dementia must be encouraged to establish their own routine(s). In addition care facilities ought to include in their planning, activities and programmes that support this process.

There was no indication to suggest that encouraging patients to establish their own routines as a basis of quality care delivery was either the practice or considered a priority on Karibu Ward. As outlined in the analysis in Chapter 7 on the rational underpinning ward schedules, care tasks were undertaken in a manner which facilitated 'getting the job done' with the maximum economy of human and material resources and within a specified time frame. This approach, which has been identified by Wilson-Barnett (1983, pp. 101-111) as 'the routine geriatric style' – as discussed in Chapter 3 – seemed to be primarily driven by the needs of ward management, coupled with carers' preferred method of care delivery rather than by patients' needs. It is important to clarify that it is not being suggested that carers deliberately gave priority to their preferred ways of managing care over the preferences or wishes of patients. Rather, it is being argued that in particular the following three distinctly independent but related factors seemed to underpin this approach to care: staff training, previous work experience and carers' understanding of dementia.

Staff Training:

- All team leaders who were registered nurses were trained according to the traditional model of nursing home care which grew out of a hospital model and has created problems by limiting 'the choice, dignity and normalcy of the individuals who reside in nursing homes' according to Rader (Rader & Tornquist 1995, p. 3). These sentiments have been identified as a feature of the medical model as outlined in Chapter 2. Carers on Karibu Ward perceived the patients as helpless, requiring assistance with all aspects of care as alluded to in Chapter 5 and

discussed more fully in Chapters 8 and 9 – a perspective consistent with the medical model. While carers were truly committed and most sincere in the task of meeting the needs of patients, the latter were perceived as passive recipients of care – a perspective which was perpetuated through the in-house training program for care assistance.

Previous Work Experience:

- The majority of carers on Karibu Ward had worked for many years on other wards in the hospital but had very limited or no experience of care settings beyond the hospital. The implications of this fact were that carers were not exposed to new understandings of dementia care or more creative approaches to practice. The possible benefits of adopting a more flexible schedule, modelled on well-established practices in other care settings did not seem to permeate the thinking or discussions of carers whenever patient care was considered.

Carers Understanding of Dementia

- Carers' understanding of dementia seemed to have its roots in the standard medical paradigm of care, which emphasised the devastating nature of the disease on individuals in term of neurological impairment. The focus was primarily on the disabilities exhibited by patients rather than on their remaining capacities as outlined in the discussions on dementia in Chapter 2. Carers did not for example reflect any knowledge of the new culture of care which emerged originally from the work of Tom Kitwood and is continuing to be developed and critiqued by many other writers in the field of dementia care. For example the concepts of embodied care and selfhood as outlined by writers such as Kontos (2004) and Basting (2003) are currently central to the discourse on dementia and important to developing new understandings of dementia. Carers perspectives on the devastating nature of the disease was also evident in the way in which problems were identified, encountered and managed with respect to patients with challenging behaviour as explored in Chapter 9.

These combined factors seemed to underpin the perpetuation of a routinised approach to care as outlined above but also influenced the priority given to meeting the physical needs of patients, which were managed in a consistently methodical way and reinforced by a strict adherence to routines.

The physical needs of patients with regard to bathing, feeding and toileting were managed as clearly defined tasks and processes within specific timeframes. Schedules relating to basic nursing care of this kind were well established as daily and/or weekly routines. Despite the limitations of routinised care as discussed above, adherence to methodical practices in this way seemed to have two particular advantages:

- basic nursing tasks of catering for the needs of patients were always given priority and were diligently carried out, irrespective of other demands on time.
- tasks involved in meeting the physical needs of patients were clearly defined and consistently met as perceived priorities in care delivery and because these approaches were routinised, it seemed relatively easy for bank/agency staff to be incorporated into a team and make a worthwhile contribution on a shift when called to do so at short notice.

This ensured relative consistency in care delivery despite the daily struggles of team leaders to find a full quota of staff for each shift.

11.1.2 Therapeutic Aspects of Care

The routines of care delivery as discussed above did not include a scheduled commitment of time, expertise and/or resources to meeting the psychosocial and spiritual needs of patients. For reasons already established with regard to training, previous work experience and carers' limited understanding of the impact of dementia on patients, the psycho-social/spiritual needs of patients did not seem to be a priority in care delivery. Despite the fact that the team leaders in particular would have had some exposure to the merits of a holistic approach to care in their nurse training – which has been an element of nursing models of care for some decades – the care model on Karibu ward seemed somewhat imbalanced from this perspective. The following facts are cited in support of this claim.

- The timeframe for each day was structured in support of catering for the physical needs of patients.
- There were no therapeutic activities such as massage or walks in the garden and/or programmes such as story telling and pet therapy in place

to assist patients who may have been feeling lonely and confused or to ensure that existing skills were not lost through lack of use as a result of a sedentary way of living

- The design and layout of the ward as discussed in Chapters 5 and 7 facilitated communal living but lacked environmental sensitivity to the needs of individual patients. Of particular significance was the lack of appropriate spaces, which it has been argued failed to provide patients with options and as a result often forced them to remain in tense and unpleasant situations without relief.
- In addition the location of the ward on the second floor deprived patients of ready access to safe walking spaces outdoors and experiences of natural sensory stimulants considered important aspects of care for people living with the deteriorating effects of memory loss. (Keegan 1998)

Despite the fact that the psychological and spiritual needs of patients were not given the same priority as their physical needs for the reasons outlined above, it is most important to stress that this does not therefore lead to the conclusion that there was no evidence of meeting the therapeutic care needs of patients. As established in Chapter 9 and in spite of the practical limitations identified above some carers and patients did form friendship bonds which seemed genuine and supportive in nature. On a number of occasions social events were also organised and much enjoyed by patients. Carers were less enthusiastic about such events due to the added work involved, the disruption to work schedules and a belief that such occasions were of no real significance to patients based on the assumption that they did not know what was going on. While it would seem that social engagements and friendship bonds did contribute in some way to the social needs of patients these were not perceived to be important elements of care and were only sustained through the goodwill and enthusiasm of individual carers.

In addition to the problems associated with the design and location of Karibu Ward, the matter of how the ward was perceived by staff in other areas of the hospital was a recurring theme among staff, especially the trained nurses. The Cinderella image of the ward, reflected in the attitudes and thinking of the nurses, tended to reinforce the negative image of dementia care, and indeed of geriatric medicine, as a 'backwater' of medical and nursing practice as explored in Chapter 3.

The qualified nurses were aware that aged care work had been seen historically as more suited to unqualified staff with low ability and limited ambition. In other words the evidence of nurses' concerns about the image of the ward tended to suggest that change is slow despite considerable development in recent years and significant commitment to research into elderly health care issues. Conversations around the perceptions of the ward always seemed to convey a feeling of low morale among staff as well as a sense of being at 'the bottom of the heap' in terms of professional standing. The latter was of considerable concern to the nurses in particular. It was their belief that the longer they stayed on Karibu Ward the more damaging it would be to their future career prospects.

The perceived image of the ward as the 'end of the line' for patients and the Cinderella of the hospital appeared to undermine staff pride in their work and their confidence in their role as professional carers. Perhaps more importantly it perpetuated a negative image of the patients, who it could be argued, had a right to expect a positive image to be projected within and outside the institution, or at least be protected from damaging perceptions of them as aged persons and as persons living with dementia.

11.2 Recommendations

As this research drew to a close I was particularly aware of the ongoing public debate regarding the dominance of the medical model in dementia care management and the rapidly growing support for alternative approaches based on development in the social sciences and reflective practice in nursing care in particular. This debate has been explored in Chapter 2, while the nursing implications have been considered in Chapter 3. From this discussion it has been concluded that the application of a medical or organic model of dementia care, including the use of drugs, undoubtedly has enhanced the physical health and cognitive functioning of patients with dementia for some years now. However, the development of a new culture of dementia care requires that we go beyond an understanding of people with dementia as simply having dysfunctional brains, to a recognition of the importance of each person's individual history and biography and whose subjective expectations can potentially inform quality care delivery.

11.2.1 The Need to Define Care According to Patient Need

As indicated in Chapter 4 the twenty patients on Karibu Ward were all classified as suffering from severe dementia or in the advanced stages of dementia.

These categories and their definitions – based on guidance supplied by the Nursing Home Registration and Inspection Unit, Lothian Health Board, 1997 — were used as a guide in the selection process in this study. According to this guidance, patients are to be identified as suffering from severe dementia when the need for physical care predominates and there is little effective interaction with others.

This guide draws a clear distinction between severe dementia and dementia with behaviour disturbance. The latter refers to patients admitted to care suffering from mild/moderate/severe dementia plus associated symptoms such as: (the) tendency to wander, mood disturbance, aggressiveness, uninhibited behaviour, which require specialist assessment and special expertise in management.

While the patients on Karibu Ward were each identified as suffering from severe dementia, evidence would suggest that it might be more appropriate to classify them as suffering from dementia with behaviour disturbance as defined in the glossary of terms and based on the analysis of issues which arose for staff in the management of patients with challenging behaviour as discussed in Chapter 9. During the process of selecting the study site for this research it was evidence of behaviour disturbance that seem to largely determine to which care setting a patient would or would not be admitted. While carers on Karibu Ward understood that the patients in their care were living and experiencing the severe stages of dementia, it was not clear from observations and interactions with them that they considered the added dimension of disturbed behaviour to be of significance in terms of approaches to care. Rather, it would appear as stated in Chapter 5 that the patients were perceived to have deteriorated into the late stages of dementia, which was often characterised by disruptive and challenging behaviour.

The two reasons given – by personnel from other care settings explored during the selection of the study site for this research - for not accepting patients with disturbed behaviour may be of significance with respect to the management of patient care on Karibu Ward. Firstly, it was recognised that patients with disturbed behaviour are likely to aggravate and disturb other patients thereby creating a tense and upsetting atmosphere for everybody. To subject patients who were not experiencing dementia or were only in the very early stages to such an environment was considered inappropriate. On Karibu Ward, however, it was assumed that the disruptive behaviour

of a patient did not have any real impact on others based on the assumption that the patients were all 'at the same stage'. However, as discussed in Chapter 7 with regard to the relationship between shared space and patient behaviour it became evident that the patients do upset and aggravate each other. This highlights the point with respect to the need for appropriate strategies for managing patients with disturbed behaviour.

Secondly, patients with severe dementia and disturbed behaviour were considered very demanding in terms of nursing care. In some care settings explored, which catered for small numbers of patients with severe dementia (without disturbed behaviour) carers worked on a rotating work schedule, -spending approximately only one month at a time with the patients before moving on to work with patient groups considered less 'demanding'. This approach may have some benefits for carers on Karibu Ward given that a rotating staff work schedule could perhaps be negotiated with other wards in the complex which caters for patients in the mild and moderate stages of dementia. While such a practice might help to relieve staff stress and the potential for burnout it is not suggested that it is an adequate substitute for the more effective management of patients with disturbed behaviour.

Making the distinction between patients with severe dementia and those with disturbed behaviour is important for the appropriate orientation and training of new staff with regard to the implications for care delivery. A number of carers had previously worked on the other three wards in the annex (which catered only for patients with mild/moderate dementia) and therefore had no training or experience of patients with severe dementia and disturbed behaviour. It is therefore being suggested that it should not be assumed – as is the current practice – that an abridged version of the in-house orientation programme is adequate for staff transferring from these wards to Karibu Ward. It is recommended therefore that specific time and training be provided for all staff for the purpose of gaining a better understanding of how best to care for patients with disturbed behaviour. It is also recommended that alternative approaches (other than medication) to managing challenging behaviour be pursued and implemented.

11.2.2 A Palliative Care Approach

In addition to the dementia categories identified above, it is becoming more commonplace to distinguish between the needs of patients living with severe dementia and those patients with dementia in the terminal stage of the illness, as discussed in Chapter 3. In the United States of America and Australia in particular, there is a

growing resource base to provide for the management of patients with advanced progressive terminal dementia in hospice and palliative care settings. While some patients on Karibu Ward were able to walk about unaided and others were chair-bound; it was the patients who were bed-ridden that appeared to fit the “terminal” category.

The introduction of a palliative care approach could assist in broadening carers' current understanding of patients comfort to include attention to their social, psychological and spiritual needs, as well as physical needs. Introducing a palliative care philosophy, as an aspect of carer orientation and training would also help carers to clarify the specific needs of individual patients, and enable them to develop appropriate care plans tailored to patients needs.

A palliative care approach need not be confined to those patients who are bed-ridden or terminal but it can be extended to incorporate a focus on the provision of active comfort care and a positive approach to reducing the symptoms of distress, disorientation and frustration that are experienced by the majority of patients on an ongoing basis. Introducing the philosophy of palliative care would ensure a more holistic approach to patient care on Karibu Ward.

Adopting a palliative approach to the care of patients would require the establishment of a multi-disciplinary team — which is consistent with practices in other elderly care settings. Such a team would consist of three or more people from different disciplines such as nurses, social workers and occupational therapists who collaborate in making decisions regarding treatment and care of patients, and also provide support and symptom control to improve the quality of living for all patients. The benefits of adopting a palliative approach to care on Karibu Ward might be readily accepted but a practical commitment to this approach would require significant resources to improve staff ratios, to re-train staff members, and provide appropriately designed facilities.

11.2.3 Ongoing Training and Development of Staff

Based on the findings of the study and expanding on the previous recommendation regarding staff training it would appear that carers' understanding of dementia could be significantly enhanced by more in-depth and comprehensive training strategies. Such strategies should include:

- insights from current research on dementia

- current knowledge and practical expertise gained from working with people with dementia and their families
- evidence concerning the impact of dementia on people; and, what constitutes high-quality care practice.

Carers could be assisted to understand that patients in their care have many characteristics in common but also have specific needs and preferences relevant to their care that are individual and unique. In this respect it would seem that carers need help to appreciate how important it is for them to get to know the patient's history, life circumstances and personality and to gain insight into the progressive impact of dementia on them over time.

From observations it would appear that carers needed to reach an understanding of the strengths and weaknesses of the medical/disease model in terms of its impact on care delivery. In this respect, carers could benefit from opportunities and skills-training in clarifying values and particularly those that underpin different forms of care delivery and are central to a psychosocial model of care. It would appear that all carers have had some exposure to the theory of holistic care; however, to effect a shift from a totally medicalised model of care towards a more person-centred approach that takes into account current discourse and insights on issues relating to memory and the pre-reflective level of functioning as integral to improved understandings of dementia and care practices. This would require a radical change of mindset and the acquisition of new skills in care delivery.

For example, instead of assuming responsibility for doing everything for patients and ensuring that they are protected at all times from any possible mishap, carers need to find new ways of maximising patients' personal control of their day-to-day living, and of balancing risk to patients with the potential gains of working with them in a different way. While the safety of patients must be always paramount, carers should be encouraged to give patients as much physical freedom as possible, aware that too much safety means the person cannot move.

Based on evidence from practice in other care settings (Kintwood 1999; Holden & Woods 1995; Douglas 1997), such training is best undertaken as close as possible to the work environment, so that staff may identify closely with their own patients' needs and all aspects of their work environment. There are now an increasing number of effective training programmes available which might be helpful. One of the most popular is the *Dementia Care Mapping* (DCM) training course, initially made available by the Bradford Research Group (Bradford Dementia Group 1996). This

training program, which is now run by many trainers who have been licensed by the Bradford Centre is primarily concerned with ensuring that the personhood of the individual with dementia is maintained. The training programme consists of structured observations over many hours of patient activities and carer-patient interactions, which are recorded on a scale.

The purpose of this approach, which is called mapping, is to provide relatively detailed feedback to staff about the quality of care received by any patient observed. This approach can provide practical feedback to carers about positive and negative aspects of how they approach care delivery. This training process is recommended for staff as a practical and realistic way of focusing on the personhood of the patient and as a way of raising their awareness of the many subtle social dynamics that underlie carer-patient encounters and care delivery.

This programme could be conducted on Karibu Ward without interfering with carers' work schedules. However, some time would have to be allotted for feedback to staff. This might be possible to schedule at periods of low activity on the ward. While DCM is widely used as a comprehensive form of training and as a service evaluation for dementia carers, there are alternative teaching methods and training packages available. For example, a team from the University of Southampton have devised and piloted an 18-week course, which has since been reduced to an eight-week course based on issues such as attachment experiences, communication, dealing with death and dying. In relation to the adoption of a palliative care approach to dementia care, such a course might be an appropriate training programme for staff members. It is not the purpose of this discussion to recommend any particular training programme, but rather to stress the importance of staff training and the need to change elements of the overall culture of care within the ward.

11.2.4 Carer-Patient Ratios

Securing a full complement of staff for each shift remained a constant challenge for team leaders during the period of observation. It would appear that the staffing levels were generally adequate to manage the workload, as currently defined in terms of priorities, even when a member of the team was an agency or bank staff member who was not so familiar with the ward. If, however, a new culture of dementia care were to be adopted, even in part, or there was a move toward implementing a palliative care approach, then the staffing levels would need to be revised and increased.

The success of a palliative care approach would require a recognition in the first place of the fact that working with patients in the advanced and terminal stages of dementia requires highly skilled carers, given the demanding and stressful nature of the work. If the psychosocial needs of the patients were to be given greater priority in care, it would be necessary for carers to work more consistently on a more individual basis with patients. For care to become more holistic or person-centred, the staff-patient ratio would possibly need to change from 1:5 to 1:4 or even 1:3, relative to the dependency levels of patients. Some experts would argue that where the physical dependency levels are high and where individuals have "terminal" conditions, the management of patients may require staff ratios of 1:2 or less, if effective relationships are to be maintained (Cheston & Bender 2000, p. 281). While staffing in some hospice care settings may reach these levels, it is unlikely that nursing homes for elderly and demented patients would do so due to cost implications. It will be difficult for changes to be made until the hospital management insist that the psycho-social needs of patients are met as a critical aspect of their overall care.

It is also recommended that it may be helpful from time to time to revise the profile of people to be admitted to the ward. Carers observed on a number of occasions that one patient on the ward was not suitably placed in terms of her needs but it was difficult to reverse the decision as time went on. It was obvious that another patient admitted during the course of data collection had possibly also been inappropriately placed, having spent many years in psychiatric care and being almost twenty years younger than other patients at the time of admission to the ward. Adherence then to a stricter admission policy and the acquisition of the skills of an occupational therapist to undertake activities with patients - as promised at the outset of the study - should all help inform the working out of more realistic staff ratios at any given time.

In this chapter, changes of both a philosophical and practical nature in dementia care have been suggested, which can only take effect through the support and leadership of management, since they are policy matters. Securing the support and cooperation of staff will be dependent in the long term on a more comprehensive training programme and career development. Any changes of the kind recommended will have cost implications, and these may be considered prohibitive. However, the real question is whether there is enough support and concern for people with dementia to ensure that public resources are made available to provide adequately for the care they and their relatives have a right to expect.

APPENDIX A:

Courtesy Letter to Committee



Mrs Jackie Warburton,
Trust Complaints Officer
St Rouge,
Astley Ainslie Hospital,
133 Grange Loan. EH 9
Edinburgh
19.12.00

DEPARTMENT of SOCIAL POLICY

The University of Edinburgh
Adam Ferguson Building
George Square
Edinburgh EH8 9LL
Fax 0131 650 3919

Email

Telephone 0131 650 1000

or direct dial 0131 650

Dear Mrs Warburton

I am a PhD student, in the Social Policy Department of the School of Social Sciences, at the University of Edinburgh. My research supervisors are: Dr Alex Robertson, Department of Social Policy, and Professor Kath Melia from the Nursing Studies Department.

My research proposal, which was accepted earlier this year, has as its focus, *the development through practice of ethical principles to guide the everyday care of people with dementia*. The emphasis here is not on dramatic ethical issues; rather the aim is to focus on everyday realities, which nurses face and manage in the process of caring for dementing elderly patients. It was felt that caring for severely demented patients would possibly highlight some of these issues in a more obvious way, given the degree of dependency on staff. As a result in the was the place finally selected for the study. In practical terms it means talking to and observing staff as they go about their daily duties of care. Observations are undertaken in public areas only such as, dining rooms, sitting rooms and corridors.

When I initially met with Dr

we discussed the issue of permission to undertake the study.

He felt that because the study was primarily focussed on staff and did not involve: observing patients in private areas such as bedrooms and or bathrooms; interviewing patients; or interviewing the relatives of patients, it was not necessary to seek the permission of the *Research Ethics Sub-Committee, Lothian Health Board* to undertake the study. The understanding was that given the manner in which data would be collected, the granting of permission was a more local issue, at the level of the

I have now started on Ward in a preliminary way. Having taken care to ensure that the purpose of my presence on the ward is clearly understood by staff, I find them amenable to the idea.

If you wish to discuss any aspects of the research as it progresses over the next few weeks, I will be very happy to do so.

Yours Sincerely,

Pauline O'Connor

APPENDIX B:

Letter of Response from Committee

Chairman: Mr Garth Morrison C.B.E.
Chief Executive: Mr David Pigott

Your Ref:
Our Ref: JEW/AMH
Enquiries to: Jackie Warburton
Ext No.: 0131 537 9522
E-Mail: Jackie.Warburton@lpct.scot.nhs.uk
Date: 16 January, 2001

LOTHIAN
PRIMARY CARE
NHS TRUST

Headquarters

St Roque Astley Ainslie Hospital
133 Grange Loan Edinburgh EH9 2HL
Tel: 0131 537 9000 Fax: 0131 537 9500
Reception: 0131 537 9525

Ms Pauline O'Connor
Dept Social Policy
University of Edinburgh
Adam Ferguson Building
George Square
EDINBURGH
EH8 9LL

Dear Ms O'Connor

I refer to your letter of 19th November 2000 regarding the project that you are undertaking in Ward, I am writing to confirm that the Trust is in agreement that this does not require ethical approval but that you have been granted management approval to undertake the research on hospital premises.

With best wishes.

Yours sincerely



 **DAVID PIGOTT**
CHIEF EXECUTIVE

APPENDIX C:

Introductory Statement

I am a PhD student in the Department of Social Policy of the School of Social Sciences at the University of Edinburgh. I am undertaking research on the subject of *the development, through practice, of ethical principles to guide the everyday care of people with dementia*.

My methodology involves participant observation, maintaining field notes, information interviews and conversations with staff members. At the completion of the study I will produce a thesis which I hope will be of use to ward staff, management and people working with and/or interested in issues arising for carers of patients with dementia.

You are invited to take part in this study. This would require you to allow me to spend time as you go about your work and to engage in informal interviews and conversations about your work.

Your involvement in the study is entirely voluntary, and non-participation will not prejudice you in any way as a staff member. Should you decide to withdraw from the study at any time you may do this without prejudice.

All personal information such as names of carers and patients will remain confidential and no information which could lead to your identification will be released to any other party. This study has been reviewed by the consultant psychiatrist for the Annex and approval has also been granted by the Chief Executive of the Lothian Primary Care NHS Trust on behalf of the Research Ethics Sub-Committee Lothian Health Board.

Should you wish to discuss the study with someone not directly involved, particularly in relation to matters concerning policies, information about the conduct of the study or your rights as a participant, or should you wish to make a confidential complaint, you may contact the Trust Complaints Officer, St Rouqe, Astley Ainslie Hospital, 133 Grange Loan. EH9. Edinburgh. Tel. 0131 537 9000. Any other enquiries you may have concerning this project should be directed to my supervisors; Dr Alex Robertson, University of Edinburgh, Department of Social Policy, Tel. 0131 650 3926; and/or Professor Kath Melia. University of Edinburgh, Professor of Nursing Studies. Tel. 01031 550 3889, or to myself on Tel. 0131 468 1171.

Pauline O'Connor
PhD Student
Department of Social Policy
University of Edinburgh.

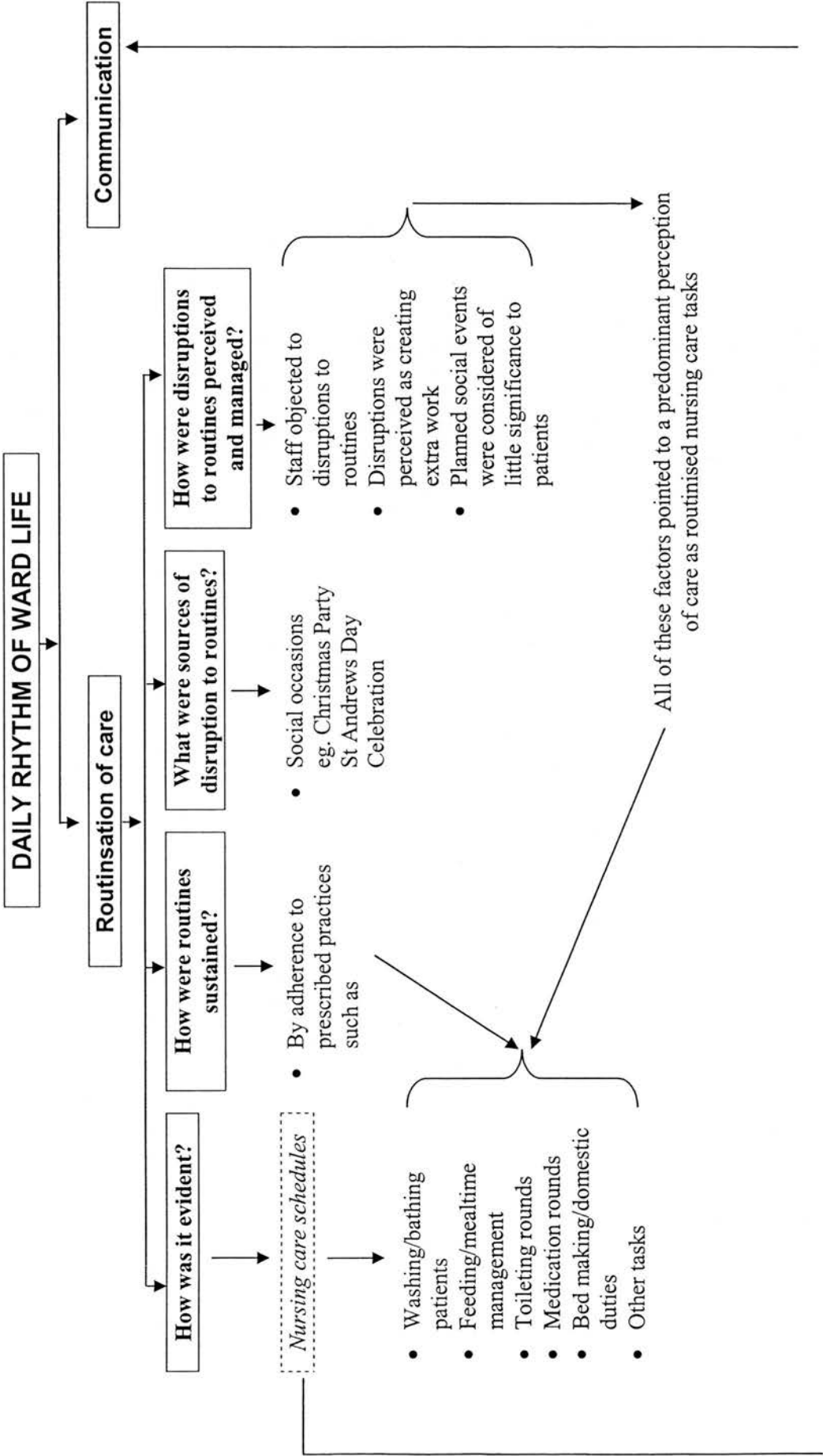
APPENDIX D: Cheat Sheet

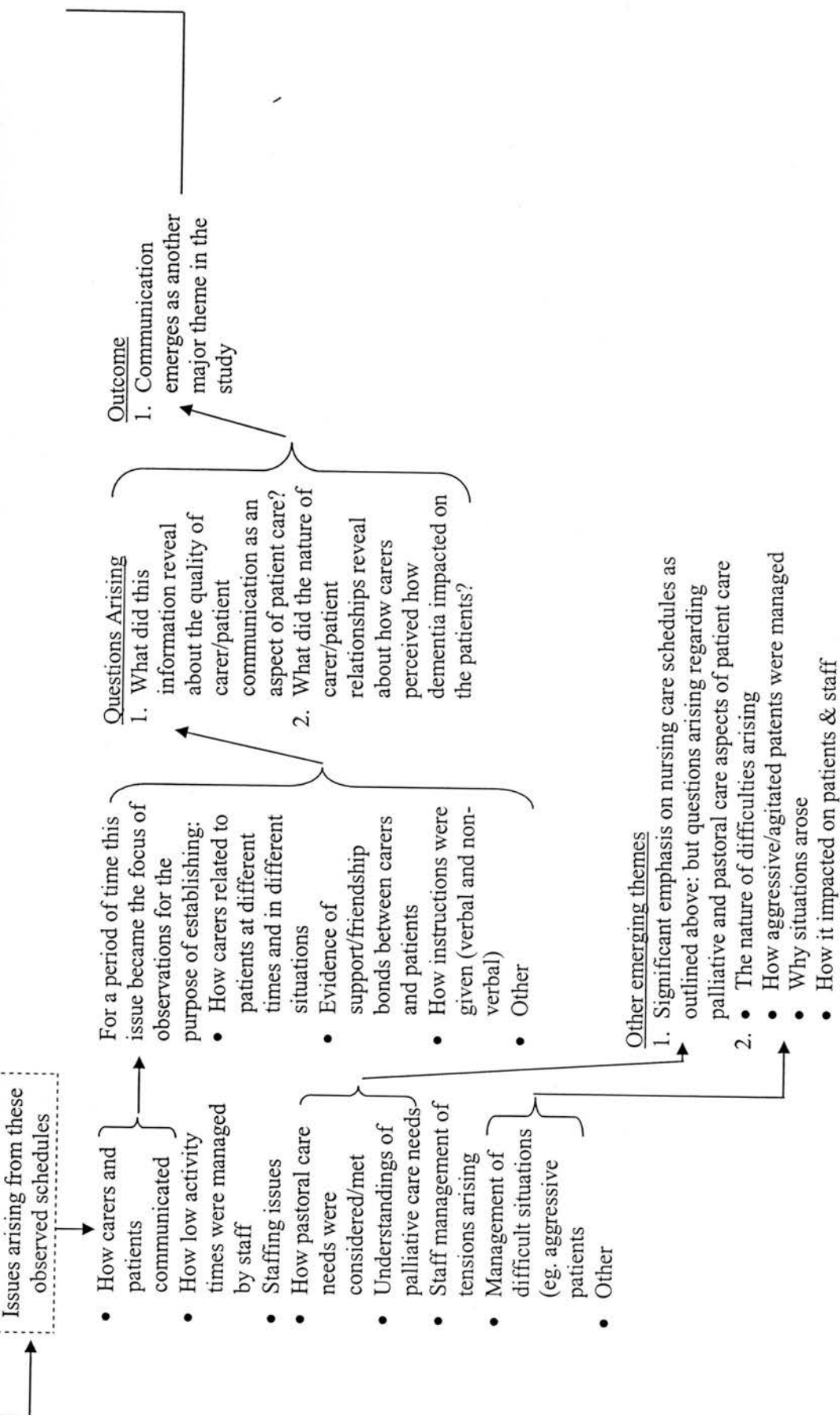
Sample

| | |
|--|--|
| Time of incident/encounter | 10.20am/DATE |
| Where did it occur? | Sitting room |
| Who was involved? | [P] Annie [NA] Karen |
| What precipitated the incident? | [P] refused to have a bath |
| Unfolding of event | [P] became agitated [NA] tried to persuade [P] [P] hit and swore at [NA] [NA] called for help |
| Outcome | [NA & N] withdrew leaving [P] to settle [P] <ul style="list-style-type: none"> • upset • crying • accepted cup of tea • nodded off to sleep [NA] somewhat dismayed at outcome |

[P] = Patient, [N] = Nurse, [NA] = Nurse Assistant

APPENDIX E: Sample of How Major Themes Emerged





APPENDIX F:

Karibu Ward: Semistructured Interview Format

1.0 Please identify your position by ticking one of the following options:

- ☐ Nurse ☐ Enrolled nurse ☐ Nurse assistant

2.0 How long have you worked on Karibu Ward? Please choose one of the following options to indicate length of time.

- ☐ 6-12 months ☐ 1-3 years ☐ 3-5 years ☐ 5 years +

3.0 Have you worked in other wards in the hospital before coming to Karibu Ward?

- ☐ Yes ☐ No

If yes, how long did you work there?

- ☐ 6-12 months ☐ 1-3 years ☐ 3-5 years ☐ 5 years+

4.0 What do you think are the priorities in your approach to caring for the patients?

5.0 From you experience of working on Karibu Ward –do you think it is necessary to have an understanding of dementia or specific training in dementia care in order to care adequately for the patients?

a) If yes, why?

b) If no, why?

6.0 Why did you choose to work on Karibu Ward?

7.0 Given that the patients on Karibu Ward are likely to deteriorate in health rather than improve over time, how does this fact influence or affect you as a carer on a day-to-day basis?

8.0 If there was an abundance of resources made available for Karibu Ward, what do you think are the three most important priorities requiring resource allocation?

REFERENCES

Glossary

- Archibald, C 1997, *Specialist dementia units: a practice guide for staff*, Dementia Services Development Centre, University of Stirling, Scotland.
- Collins Compact Dictionary* 2002, Harper Collins Publishers, Glasgow.
- Davies, C 1995, *Gender and the professional predicament in nursing*, Open University Press, Buckingham.
- Goldsmith, M 1998, *Hearing the voice of people with dementia*, Jessica Kingsley Publishers, London.
- Holden, U & Woods, RT 1995, *Positive approaches to dementia care*, 3rd edn, Churchill Livingstone, Edinburgh.
- Jacques, A & Jackson, GA 2000, *Understanding dementia*, Churchill Livingstone, Edinburgh.
- Lothain Health Board 1997, *Nursing home registration and inspection unit: explanations of categories of care*, Deaconess House, 148 Pleasance, Edinburgh.
- Rader, J & Tornquist EM (eds.) 1995, *Individualized dementia care: creative, compassionate approaches*, Springer Publishing Company, New York.
- Sheard, D & Cox, S (eds.) 1998, *Teams, multidisciplinary and interprofessional working and dementia*, Dementia Services Development Centre, University of Stirling, Scotland.
- Volicer, L & Hurley, A 1998, *Hospice care for patients with advanced progressive dementia*, Springer Publishing Company, New York.

Prologue: Roots of the Concerns Informing this Research

- Adams, T & Clarke CL 1999, *Dementia care, developing partnerships in practice*, Bailliere Tindall, London.
- Age Concern Scotland 1999, *Turning your back on us: older people and the NHS*, Age Concern Scotland, Edinburgh.
- Age Concern Scotland 2002, *Older people in Scotland: some basic facts*, Age Concern Scotland, Edinburgh.
- Alzheimer Scotland - Action on Dementia 1996, *Putting quality first: the need to improve long-stay care for people with dementia*, Action on Dementia, Edinburgh.

- Archibald, C 1997, *Specialist dementia units: a practice guide for staff*, Dementia Services Development Centre, University of Stirling, Scotland.
- Beck, CT 1996, 'Nursing student's experiences caring for cognitively impaired elderly people', *Journal of Advanced Nursing*, vol. 23, pp. 992-998.
- Chapman, A & Kerr, D 1995, *Person-centred approach to care*, Dementia Services Development Centre, University of Stirling, Scotland.
- Collins English Dictionary* 1998, 4th edn, Harper Collins Harper Publishers, Glasgow.
- Harding, N & Palfrey, C 1997, *The social construction of dementia: confused professionals?* Jessica Kingsley Publishers, London.
- Help the Aged 1996, *Challenge on care*, Help the Aged, London.
- Holden, UP & Woods, RT 1995, *Positive approaches to dementia care*, 3rd edn, Churchill Livingstone, Edinburgh.
- Jacobzone, S & Oxley, J 2002, 'Ageing and health care costs', *Internationals Politik und Gesellschaft Online (International Politics and Society)*. Retrieved 10 January, 2003, from http://fesportal.fes.de/pls/portal30/docs/FOLDER/IPG/IPG1_2002/ARTJACOBZONE.HTM
- Jacobzone, S 2000, 'Coping with ageing: a comparison among industrialized countries', *Health Affairs*, vol. 19, pp. 213-215.
- Kitwood, T 1999, *Dementia reconsidered: the person comes first*, Open University Press, Buckingham.
- Melia, KM 1989, *Everyday nursing ethics*, Macmillan, London.
- Norman, IJ 1999, 'Person-centred dementia care', in SJ Redfern & FM Ross (eds.), *Nursing Older People*, 3rd edn, Churchill Livingstone, Edinburgh.
- Pearson, A 1998, 'Nursing quality measurement', in J Marr & B Kershaw (eds.), *Caring for older people: developing specialist practice*, ARNOLD, London, p. 291.
- Pickering, S & Thompson, JS (eds.) 1998, *Promoting positive practice in nursing older people: perceptions on quality of life*, Bailliere Tindall, London.

Chapter 1: Demographic, Funding & Service Trends in Care Delivery

- Accounts Commission 2000, *Commissioning community care services for older people: applying a best value framework*, Accounts Commission, Edinburgh.
- Age Concern Scotland 1999, *Community care for older people: age concern. Scotland's response to the white paper – modernising community care: an action plan*, Age Concern Scotland, Edinburgh.

- Age Concern Scotland 2000, *Older people in Scotland: some basic facts 1999-2000 Fact Card*, Age Concern Scotland, Edinburgh.
- Alzheimer Scotland - Action on Dementia 1996, *Putting quality first: the need to improve long-stay care for people with dementia*, Action on Dementia, Edinburgh.
- Alzheimer Scotland 1999, *The quality challenge: caring for people with dementia in residential institutions in Europe*, Action on Dementia, Edinburgh.
- Archibald, C 1997, *Specialist dementia units: a practice guide for staff*, Dementia Services Development Centre, University of Stirling, Scotland.
- Audit Commission 1997, *The coming of age: improving care services for older people*, HMSO, London.
- Bosenquet, N, May, J & Johnson, N 1998, *Alzheimer's disease in the United Kingdom: burden of disease and future care*, health policy review paper, Imperial College, University of London, London.
- Briggs, K & Askham, J 1999, *The needs of people with dementia and those who care for them*, Alzheimer's Dementia Care and Research, London.
- Cameron, K, Chapman, A (eds.) 2000, *CarenapD: care needs assessment pack for dementia*, Dementia Services Development Centre, University of Stirling, Scotland.
- Centre for Policy on Ageing (CPA) 1984, *Home life: a code of practice for residential care*, CPA, London.
- Centre for Policy on Ageing (CPA) 1996, *A better home life: a code for good practice for residential and nursing home care*, CPA, London.
- Cox, S, Anderson, I, Dick, S & Elgar, J 1998, *The person, the community and dementia: developing a value framework*, Dementia Services Development Centre, University of Stirling, Scotland.
- Dellasega, C & Nolan, M 1997, 'Admission to care: facilitating role transition amongst family carers', *Journal of Clinical Nursing*, vol. 6, pp. 443-451.
- Department of Health and Social Services Inspectorate (DOH/SSI) 1989, *Homes are for living in: a model for evaluating quality of care provided and the quality of life experienced in residential care homes for elderly people*, HMSO, London.
- Department of Health and Social Services Inspectorate (DOH/SSI) 1990, *Guidance on standards for residential homes for elderly people*, HMSO, London.
- Department of Health and Social Services Inspectorate (DOH/SSI) 1993, *Standards for the residential care of elderly people with mental disorders*, HMSO, London.
- Department of Trade and Industry 1998, *Home Accidents Surveillance System*, annual report, Department of Trade and Industry, London.
- Downs, M & Marshall, M 1997, *Scottish needs assessment programme priority services network, dementia*, Scottish Forum for Public Health Medicine, Glasgow.

- Elgar, J & Marshall, M 1998, *Dementia: a practice guide for registration and inspection staff*, Dementia Services Development Centre, University of Stirling, Scotland.
- Foucault, M 1967, *Madness and civilization*, Tavistock, London.
- General Register Office for Scotland 1998, *Population estimates*, General Register Office for Scotland, Scotland.
- Glennerster, H 1996, *Caring for the very old: public and private solutions*, discussion paper, London School of Economics, London.
- Goffman, E 1963, *Stigma*, Prentice Hall, Englewood Cliffs, New Jersey.
- Goldsmith, M, Kindred, M, Innes, A, Chapman, C (eds.) 1997, *Hearing the voice of people with dementia: a study guide*, Dementia Services Development Centre, University of Stirling, Scotland.
- Gordon, D 1999, 'New estimates of the prevalence of dementia', in Alzheimer Scotland, *The quality challenge: caring for people with dementia in residential institutions in Europe*, Action on Dementia, Edinburgh.
- Gordon, DS, Carter, H, Scott, HS 1995, *The needs of elderly people with problems of memory/confusion*, survey report, Fort Valley Health Board, Stirling.
- Gordon, D, Carter, H, Scott, S 1997, 'Profiling the care needs of the population with dementia: a survey in Central Scotland', *International Journal of Geriatric Psychiatry*, vol. 12, pp. 753-759.
- Government Actuary with Registrars General 1996, *Population projections 1996-2036*, Government Actuary with Registrars General, Scotland
- Harvey, R 1998, *Young onset dementia: epidemiology, clinical symptoms, family burden, support and outcome*, Imperial College of Science, Technology and Medicine, London.
- Heath, H & Schofield, I 1998, *Healthy ageing: nursing older people*, Mosby, Italy.
- Hofman, A, Rocca, W, et al. 1991, 'The prevalence of dementia in Europe: a collaborative study of 1980-1990 findings', *International Journal of Epidemiology*, vol. 20, no. 3, pp. 736-748.
- Holmes, J, Pugener, K et al. 1998, 'Managing Alzheimer's disease: the cost of care per patient', *British Journal of Health Care Management*, vol. 4, no. 7, pp. 332-337.
- Hunter, S (ed.) 1997, *Dementia: challenges and new directions*, Jessica Kingsley Publishers, London.
- Illich, I 1975, *Medical nemesis: the expropriation of health*, Calder and Boyars, London.
- Jacques, A & Jackson, G 2000, *Understanding dementia*, 3rd edn, Churchill Livingstone, Edinburgh.
- Jorm, A, Korten, A, et al. 1987, 'The prevalence of dementia: a quantitative integration of the literature', *Acta Psychiatr*, vol. 76, pp. 465-479.

- Keen, J 1993, 'Dementia: questions of cost and value', *International Journal of Geriatric Psychiatry*, vol. 8, pp. 369-378.
- Kenny, D 1997, 'The medical perspective', in K Allan (ed.), *Care for people with dementia in acute ward settings*, Dementia Services Development Centre, University of Stirling, Scotland.
- Kitwood, T 1997, *Dementia reconsidered: the person comes first*, Open University Press: Buckingham
- Kokmen, E, Beard, C, Offord, K, Kurland, L 1989, 'Prevalence of medically diagnosed dementia in a defined United States Population', *Neurology*, vol. 39, pp. 773-776.
- Levin, E, Sinclair, I, Gorbach, P 1989, *Families, services and confusion in old age*, Avebury, Aldershot.
- Livingstone, G, Maca, M, et al. 1997, 'Costs of community care for older people', *British Journal of Psychiatry*, vol. 171, pp. 56-69.
- MacDonald, C & Teven, T 1997, *Who's in control?* Dementia Services Development Centre, University of Stirling, Scotland.
- Marr, J & Kershaw, B (eds.) 1998, *Caring for older people: developing specialist practice*, Arnold, London.
- Marshall, M 1997, *Design for dementia: six conference papers*, Dementia Services Development Centre, University of Stirling, Scotland.
- Norman, A 1987, *Severe dementia: the provision of long-stay care*, Centre for Policy on Ageing, London.
- Office of Fair Trading (OFT) 1998, *Older people as consumers in care homes*, OFT, London.
- Peace, S, Kellaher, L & Willcocks, D 1997, *Re-evaluating residential care*, Open University Press, Buckingham.
- Rowntree, J 1997, *Meeting the costs of continuing care*, Joseph Rowntree Foundation, York.
- Schneider, J, Kavanagh, S, et al. 1993, 'People with advanced cognitive impairment in England: resources use and costs', *Ageing and Society*, vol. 13.
- Scottish Executive 2000a 'Aiming for excellence – modernizing social work services in Scotland', *Draft national care standards*, first tranche, consultation paper, Scottish Executive, Scotland.
- Scottish Executive 2000b, *Response to the royal commission on long term care*, Scottish Executive, Scotland.
- Scottish Executive 2000c, *The way forward for care: a policy position paper*, Scottish Executive, Scotland.
- Scottish Executive 2002, *The Scottish Commission for the Regulation of Care: care regulation is changing*, Retrieved February 15, 2006 from <http://www.scotland.gov.uk/Library3/health/scrc-00.asp>

Scottish Executive 2003a, *Introduction: mental health*, Retrieved January 21, 2006, from <http://www.scotland.gov.uk/Topics/Health/health/mental-health/Intro>

Scottish Executive 2003b, *Parliament passes mental health bill*, media release, Retrieved January 20, 2006, from <http://www.scotland.gov.uk/news/releases/2003/03/3366>

Scottish Executive 2005c, *Free personal care: introduction*, Retrieved February 6, 2006, from <http://www.scotland.gov.uk/Topics/Health/care/17655/9334>

Scottish Executive 2005b, *Current research: research to evaluate implementation and impact of the policy*, Retrieved February 6, 2006, from <http://www.scotland.gov.uk/Topics/Health/care/17655/research>

Scottish Executive 2005a, *Better outcomes for older people: framework for joint services*, Retrieved February 6, 2006, from <http://www.scotland.gov.uk/Publications/2005/05/13101338/14143>

Scottish Intercollegiate Guidelines Network 2001, *Hypertension in older people: a national clinical guideline*, Scottish Intercollegiate Guidelines Network, Scotland.

Warnes, AM 1996, 'The demography of old age: panic versus reality', in R Bland (ed.), *Developing services for older people and their families*, Jessica Kingsley Publishers, London.

Wilkin, D & Hughes, B 1987, 'Residential care of elderly people: the consumers views', *Ageing and Society*, vol. 7, no. 2, pp. 175.

Legislation

Adults with Incapacity (Scotland) Act 2000, Retrieved January 29, 2006, from <http://www.scotland.gov.uk/Publications/2005/08/23175953/59590>

Mental Health (Care and Treatment) (Scotland) Act 2003, Retrieved January 20, 2006 from <http://www.scotland.gov.uk/Topics/Health/health/mental-health/mhlaw/the2003Act>

Regulation of Care (Scotland) Act 2001, Retrieved January 20, 2006, from <http://www.opsi.gov.uk/legislation/scotland/acts2001/20010008.htm>

Chapter 2: Understanding Dementia

Abbott, P & Meerabeau, L 1998, *The sociology of the caring profession*, 2nd edn, UCL Press, London.

Adams, T 1996, 'Kitwood's approach to dementia and dementia care: a critical but appreciative review', *Journal of Advanced Nursing*, vol. 23, no. 5, pp. 948-953.

Adams, T & Clarke, C 1999, *Dementia care: developing partnerships in practice*, Bailliere Tindell, London.

- Adams, T & Gardiner, P 2005, 'Communication and interaction within dementia care triads: developing a theory for relationship-centred care', *Dementia*, vol. 4, no. 2. pp. 185-206.
- Audo, R 1997, *Moral knowledge and ethical character*, Oxford University Press, New York.
- Basting, AD 2003, 'Looking back from loss: views of the self in Alzheimer's disease', *Journal of Ageing Studies*, vol. 17, pp.87-99.
- Beauchamp, TL & Childress, JF 1994, *Principles of biomedical ethics*, 4th edn, Oxford University Press, New York.
- Bourdieu, P 1984, *Distinction: A social critique of the judgement of taste*, Harvard University Press, Cambridge, Massachusetts.
- Chester, R & Bender, M 1999, *Understanding dementia: the man with the worried eyes*, Jessica Kingsley Publishers, London.
- Davis, DHJ 2004, 'Dementia: sociological and philosophical constructions', *Social Science and Medicine*, vol. 58 pp. 369-378.
- Downs, M & Marshall, M 1997, *Scottish needs assessment programme priority services network, dementia*, Scottish Forum for Public Health Medicine, Glasgow.
- Edwards, SD 1996, *Nursing ethics*, Macmillan, London.
- Fox, P 1989, 'From senility to Alzheimer's disease: the rise of Alzheimer's disease movement', *Millbank Quarterly*, vol 67, pp. 58-103.
- Fraser, M 1987, *Dementia: its nature and management*, John Wiley & Sons, New York.
- Gelder, M, Gath, D & Mayou, R 1989, *Oxford textbook of psychiatry*, 2nd edn, Oxford University Press, Oxford.
- Glaser, BG 1978, *Theoretical sensitivity*, Sociological Press, Mill Valley, California.
- Glaser, BG & Strauss, AL 1965, *Awareness of dying*, Aldine, Chicago.
- Golander, H & Raz, A 1996, 'The mask of dementia: images of 'demented residents' in a nursing ward', *Ageing and Society*, vol. 16, pp.269-285.
- Goldsmith, M 1998, *Hearing the voice of people with dementia: opportunities and obstacles*, Jessica Kingsley Publishers, London.
- Greenwood, D, Loewenthal, D & Rose, T 2001, 'A relational approach to providing care for a person suffering from dementia', *Journal of Advanced Nursing*, vol. 36, p. 583.
- Gubrium, J 1986, *Old timers and Alzheimer's: the descriptive organization of senility*, JAI Press, Greenwich.
- Harding, N & Palfrey, C 1997, *The social construction of dementia: confused professionals?* Jessica Kingsley Publishers, London.

- Hellstrom, I, Nolan, M & Lindh, U 2005, 'Awareness context theory and the dynamics of dementia: improving understanding using emergent fit', *Dementia*, vol. 4, no. 2, pp. 270-297.
- Holden, UP & Woods, RT 1995, *Positive approaches to dementia care*, Churchill Livingstone, Edinburgh.
- Isaac, B 1981, 'Is geriatrics a speciality?', in T Arie (ed.), *Health care of the elderly*, Croom Holm, London.
- Jacques, A & Jackson, GA 2000, *Understanding dementia*, 3rd edn, Churchill Livingstone, Edinburgh.
- Jones, G & Miesen, BML (eds.) 1996, *Care-giving in dementia*, Routledge, London.
- Keady, J 1999 *The Dynamics of dementia: A modified grounded theory study*, PhD thesis, University of Wales, Bangor.
- Kitwood, T 1990, 'The dialectics of dementia: with particular reference to Alzheimer's disease', *Ageing and Society*, vol. 10, pp. 177-196.
- Kitwood, T 1993, 'Towards the reconstruction of an organic mental disorder', in A Radley (ed.), *Worlds of disorder*, Routledge, London.
- Kitwood, T 1997, *Dementia reconsidered: the person comes first*, Open University Press, Buckingham.
- Kitwood, T & Bredin, K 1992, 'Toward a theory of dementia care: personhood and well-being', *Ageing and Society*, vol. 12, pp. 269-287.
- Kontos, PC 2005, 'Embodied selfhood in Alzheimer's disease: rethinking person-centred care', *Dementia*, vol. 4, no. 4, pp. 553-570.
- Kontos, PC 2004, 'Ethnographic reflections on selfhood, embodiment and Alzheimer's disease', *Ageing and Society*, vol. 24, pp. 829-849.
- Lishman, WA 1987, *Organic psychiatry: the psychological consequences of cerebral disorder*, 2nd edn, Blackwell, Oxford.
- Marshall, M 1990, *Working with dementia*, Venture Press, Birmingham.
- Marshall, M 1996, *'I can't place this at all': working with people with dementia and their carers*, Venture Press, Birmingham.
- Merleau-Ponty, M 1962, *Phenomenology of Perception*, Routledge and Kegan Paul, London.
- Monasterio, X 1985, *To be human*, Paulist Press, New York.
- Morton, I 1997, 'Beyond validation', in IJ Norman & SJ Redfern (eds.), *Mental health care for elderly people*, Churchill Livingstone, New York.
- Murphy, E 1986, *Dementia and mental illness in old age*, Macmillan, Basingstoke.

- Nolan, M, Ryan, T, Enderby, P & Reid D 2002, 'Towards a more inclusive vision of dementia care practice', *Dementia: The International Journal of Social Research and Practice*, vol. 1, no. 2, pp. 193-211.
- Norman, A 1982, *Mental illness in old age: meeting the challenge*, Centre for Policy on Ageing, London.
- Norman, IJ 1999, 'Person-centred dementia care', in SJ Redfern & FM Ross (eds.), *Nursing older people*, Churchill Livingstone, Edinburgh.
- Norman, IJ & Redfern, SJ (eds.) 1997, *Mental health care for elderly people*, Churchill Livingstone, New York.
- Novack, DH, et al. 1989, 'Physicians attitudes toward using deceptions to resolve difficult ethical problems', *Journal of the American Medical Association*, vol. 261, pp. 2980-2985.
- Parker, J & Penhale, B 1998, *Forgotten people: positive approaches to dementia care*, Ashgate, Aldershor.
- Pearson, A, Vaughan, B & Fitzgerald, M 1998, *Nursing models for practice*, 2nd edn, Butterworth Heinemann, Oxford.
- Redfern, SJ & Ross, FM (eds.) 1999, *Nursing older people*, 3rd edn, Churchill Livingstone, Edinburgh.
- Rowson, R 1990, *An introduction to ethics for nurses*, Mosby, London.
- Satre, JP 1948, *Existentialism and humanism*, Methuem, London.
- Stokes, G & Goudie, F (eds.) 1999, *Working with dementia*, Winslow Press, Oxon.
- Taylor, C 1989, *The sources of the self*, Cambridge University Press, Cambridge.
- Thompson, IE, Melia, KM & Boyd, KM 1996, *Nursing ethics*, 3rd edn, Churchill Livingstone, Edinburgh.
- Tornier, P 1974, *The meaning of persons*, SPCK, London.
- Tschudin, V 1999, *Ethics in nursing: the caring relationship*, 2nd edn, Butterworth Heinmann, Oxford.
- World Health Organisation (WHO) 1986, *Dementia in later life: research and action. Report of a WHO scientific group on senile dementia*, WHO Technical Report Series 730, World Health Organisation, Geneva.

Chapter 3: Understanding Nursing Care Practice

- Abraham, C & Shanley, E 1992, *Social psychology for nurses: understanding interaction in health care*, Edward Arnold, London.
- Adams, T & Clarke, CL 1999, *Dementia care: developing partnerships in practice*, Bailliere Tindall, London.
- Alexander, C 1997, *A pattern language*, Oxford University Press, New York.
- Barnett, E 1997, 'Listening to people with dementia and their carers', in M Marshall (ed.), *State of the art in dementia care*, Centre for Policy and Ageing, London.
- Benner, P 1984, *From novice to expert*, Addison-Wesley Publishing Company, London.
- Bishop, AH & Scudder (Jr), JR 1991, *Nursing: the practice of caring*, National League for Nursing Press, New York.
- Bowden, P 1997, *Care gender-sensitive ethics*, Routledge, London.
- Brykczynska, G & Jolley, M (eds.) 1997, *Caring: the compassion and wisdom of nursing*, Arnold, London.
- Burnard, P & Chapman, CM 1999, *Professional and ethical issues in nursing: the code of professional conduct*, 2nd edn, Bailliere Tindall, Edinburgh.
- Campbell, AV 1984, *Moderated love*, SPCK, London.
- Caper, BA 1997, 'Fundamental patterns of knowing in nursing', in P Rose & D Parker (eds.), *Advancing nursing practice: a reader*, The University of Greenwich, Greenwich.
- Collins English Dictionary* 1998, 4th edn, Harper Collins Harper Publishers, Glasgow.
- Cox, S, Anderson, I, Dick, S & Elgar, J 1998, *The person, the community and dementia: developing a value framework*, Dementia Services Development Centre, University of Stirling, Scotland.
- Davies, C 1995, *Gender and the professional predicament in nursing*, Open University Press, Buckingham.
- Department of Health and Ageing 2004, 'Guidelines for a palliative approach in residential aged care', *The National Palliative Care Program*, Department of Health and Ageing, Canberra.
- Elgar, J & Marshall, M 1998, *Dementia: a practice guide for registration and inspection staff*, Dementia Services Development Centre, University of Stirling, Scotland.
- Evans, L & Strump, N 1989, 'Tying down the elderly: a review of the literature on physical restraints', *Journal of American Geriatrics Society*, vol. 37, no. 1, pp. 65-74.
- Fagermoen, MS 1997, 'Professional identity: values embedded in meaningful nursing practice', in P Rose & D Parker (eds.), *Advancing nursing practice: a reader*, University Press: Greenwich.

- Felce, D & Perry, J 1995, 'Quality of life: its definition and measurement', *Research in Development Disabilities*, vol. 16, pp. 51-74.
- Fosbinder, D 1994, 'Patients perceptions of nursing care: an emerging theory in interpersonal competence', *Journal of Advanced Nursing*, vol. 20, pp. 1085-1093.
- Harding, N & Palfrey, C 1997, *The social construction of dementia: confused professionals?*, Jessica Kingsley Publishers, London.
- Heath, J & Schofield, I 1999, *Healthy ageing: nursing older people*, Mosby, Italy.
- Holden, U & Woods, RT 1995, *Positive approaches to dementia care*, 3rd edn, Churchill Livingstone, Edinburgh.
- Hughes, B & Wilkin, D 1987, 'Physical care and quality of life in residential homes', *Ageing and Society*, vol. 7, no. 4, p. 414.
- Jolley, M & Allan, P (eds.) 1989, *Current issues in nursing*, Chapman and Hall, London.
- Kaganowski, MA 1997, 'A commitment to palliative care', *Journal of Gerontological Nursing*, vol. 23, no. 3, pp. 36-42.
- Kayser-Jones, JS 1981, 'Quality of care for the institutionalized aged: a Scottish American comparison', in CL Fry (ed.) *Dimension ageing: culture and health*, Praeger, New York.
- Killick, J & Allan 2001, K, *Communication and the care of people with dementia*, Open University Press, Buckingham.
- Kitson, AL 1987, 'Raising standards of clinical practice: the fundamental issues of effective nursing care', *Journal of Advanced Nursing*, vol. 12, pp. 321-329.
- Lawler, J 1991, *Behind the screens: nursing, somology and the problem of the body*, Churchill Livingstone, Melbourne.
- Lawton, MP 1991, 'A multi-dimensional view of quality of life in frail elders', in J Binet, J Lubben, J Rose & D Deutchman (eds.), *The concept and measurement of quality of life in the frail elderly*, Academic Press, New York.
- Marr, J & Kershaw, B (eds.) 1998, *Promoting positive practice in nursing older people*, Bailliere Tindall, London.
- Mayeroff, M 1972, *On caring*, Harper and Row, New York.
- McGroth, A, Reid, N & Boore, J 1989, 'Occupational stress in nursing', *International Journal of Nursing Studies*, vol. 26, pp. 343-358.
- Meltzer, BN, Petras, JW & Reynolds, LT 1975, *Symbolic interactionism: genesis, varieties and criticisms*, Routledge, London.
- Miesen, BML & Jones, GMM (eds.) 1997, *Care-giving in dementia*, vol. 2, Routledge, London.
- Molony, SL, Waszynski, CM & Lyder, CH 1999, *Gerontological nursing: an advanced practice approach*, Appleton & Lange.

- Norman, IJ & Redfern, SJ (eds.) 1997, *Mental health care for elderly people*, Churchill Livingstone, New York.
- O'Neill, PA 2002, *Caring for older adults: a health promotion perspective*, WB Saunders Company, Philadelphia.
- Pickering, S & Thompson, JS (eds.) 1998, *Promoting positive practice in nursing older people: perceptions on quality of life*, Bailliere Tindall, London.
- Purtilo, B & Cassel, CK 1981, *Ethical dimensions in the health professions*, WB Saunders Company, Philadelphia.
- Rader, J & Tornquist, EM (eds.) 1995, *Individualised dementia care: creative, compassionate approaches*, Springer Publishing Company, New York.
- Ray, M 1999, 'Developing person-centred standards for care homes', *Journal of Dementia Care*, vol 17.
- Redfern, SJ & Ross, FM 1999, *Nursing older people*, 3rd edn, Churchill Livingstone, Edinburgh.
- Savage, J 1995, *Nursing intimacy: an ethnographic approach to nurse-patient interaction*, Scutari Press, London.
- Stokes, G 1990, 'The environmental context', in G Stokes & F Goudie (eds.), *Walking with dementia*, Winslow Press, Oxon.
- Stokes, G & Goudie, F (eds.) 1999, *Working with dementia*, Winslow Press, Oxon.
- Street, A 1995, *Nursing Replay*, Churchill Livingstone, Melbourne.
- Thompson, IE, Melia, KM & Boyd, KM 1996, *Nursing Ethics*, 3rd edn, Churchill Livingstone, Edinburgh.
- Tschudin, V 1986, *Ethics in nursing: the caring relationship*, Heinemann Nursing, London.
- Tschudin, V 1999, *Ethics in nursing: the caring relationship*, 2nd edn, Butterworth Heinemann, Oxford.
- Vetter, NJ, Jones, DA & Victor, CR 1988, 'The quality of life of the over 70s in the community', *Health Visitor*, vol. 61, pp. 10-13.
- Volicer, L & Bloom-Charette, L (eds.) 1999, *Enhancing the quality of life in advanced dementia*, BRUNNER/MAZE, Philadelphia.
- Volicer, L, Brandeis, G & Hurley AC 1998, 'Infections in advanced dementia', in L Volicer & A Hurley (eds.), *Hospice care for patients with advanced progressive dementia*, Springer Publishing Company, New York.
- Volicer, L & Hurley, A 1998, *Hospice care for patients with advanced progressive dementia*, Springer Publishing Company, New York.
- Wilson-Barnett, J 1994, 'The nurse-patient relationship', in R Gillon (ed.), *Principles of health care ethics*, John Wiley & Sons, Chichester.

Chapter 4: Research Design

- Basting, AD 2003, 'Looking back from loss: views of the self in alzheimer's disease', *Journal of Ageing Studies*, vol. 17, pp. 87-99.
- Blaikie, N 1993, *Approaches to social enquiry*, Polity Press, Cambridge.
- Blaikie, N 2000, *Designing social research: the logic of anticipation*, Polity Press, Cambridge.
- Boyle, J 1991, 'Field research: a collaboration model for practice and research', in J Morse (ed.) *Qualitative nursing research: a contemporary dialogue*, Sage, California.
- Bryman, A 2004, *Social Research Methods*, 2nd edn, Oxford University Press, New York.
- Bryman, A & Burgess, RG 1994, *Analyzing qualitative data*, Routledge, London.
- Bulmer, M (ed.) 1984, *Sociological research methods: an introduction*, 2nd edn, Macmillan Publishers, London.
- Burns, RB 2000, *Introduction to research methods*, SAGE Publications, London.
- Coffey, A & Atkinson, P 1996, *Making sense of qualitative data: complementary research strategies*, SAGE Publications, Thousand Oaks.
- Creswell, JW 1998, *Qualitative inquiry and research design: choosing among five traditions*, SAGE Publications, Thousand Oaks.
- Davis, DHJ 2004, 'Dementia: sociological and philosophical constructions', *Social Science and Medicine*, vol. 58, pp. 369-378.
- Field, PA & Morse, JM 1985, *Nursing research: the application of qualitative approaches*, Croon Helm, London.
- Fisher, M 1995, 'Desktop tools for the social scientist', in RM Lee (ed.), *Information technology for the social scientist*, UCL Press, London.
- Glaser, BG & Strauss, AL 1967, *The discovery of grounded theory: strategies for qualitative research*, Aldine, Chicago.
- Hellstrom, I, Nolan, M & Lundh, U 2005, 'Awareness context theory and the dynamics of dementia: improving understanding using emergent fit', *Dementia*, vol. 4, no. 2, pp. 270-289.
- Kontos, PC 2005, 'Embodied selfhood in alzheimer's disease: rethinking person-centred care', *Dementia*, vol. 4, no. 4, pp. 553-570.
- Lawler, J 1991, *Behind the screens: nursing, somology and the problem of the body*, Churchill Livingstone, Melbourne.
- Melia, KM 1987, *Learning and working: the occupational socialization of nurses*, Tavistock Publications, London.
- Polit, DF & Hungler, BP 1999, *Nursing research*, Lippincott, Philadelphia.

- Sapsford, R & Jupp, V (eds.) 1998, *Data collection and analysis*, SAGE Publications, London.
- Savage, J 1995, *Nursing intimacy: an ethnographic approach to nurse-patient interaction*, Scutari Press, London.
- Schatzman, L & Strauss, AL 1973, *Field research: strategies for a natural sociology*, Prentice Hall, New Jersey.
- Schwandt, TA 1994, 'Constructivist, interpretivist approaches to human inquiry', in NK Denzin & YS Lincoln (eds.), *Handbook of qualitative research*, SAGE Publications, Thousand Oaks.
- Schwartz, H & Jacobs, J 1979, *Qualitative sociology: a method to the madness*, Free Press, New York.
- Strauss, AL 1987, *Qualitative analysis for social scientists*, Cambridge University Press, Cambridge.
- Watson, J 1988, *Nursing: human science and human care: a theory of nursing*, National League for Nursing, New York.
- Willer, D 1967, *Scientific Method: Theory and Method*, Prentice-Hall, Englewood Cliffs, New Jersey.
- Woods, P 1979, *The divided school*, Routledge & Kegan Paul, London.

Chapter 5: Ward Layout, Furniture & Equipment

- Archibald, C 1997, *Specialist dementia units: a practice guide for staff*, Dementia Services Development Centre, University of Stirling, Scotland.
- Denham, MJ (ed.) 1997, *Continuing care for older people*, Stanley Thornes Publishers, Cheltenham.
- Goldsmith, M, Kindred, M, Innes, A & Chapman, C (eds.) 1997, *Hearing the voice of people with dementia: a study guide*, Dementia Services Development Centre, University of Stirling, Scotland.
- Hooper, B & Parker, T 2000, 'Restlessness and wandering', in S Benson (ed.), *The care assistant's guide to working with people with dementia*, 3rd edn, Hawker Publications, London.
- Jenkins, DAL 1999, *Intimate caring skills: urinary and faecal incontinence: a heightened problem when dementia is a factor*, Dementia Services Development Centre, University of Stirling, Scotland.
- Kitwood, T 1997, *Dementia reconsidered: the person comes first*, Open University Press, Buckingham.

- Marshall, M 1997, *State of the art in dementia care*, Centre for Policy on Ageing, London.
- Rader, J & Tornquist, EM (eds.) 1995, *Individualised dementia care: creative, compassionate approaches*, Springer Publishing Company, New York.
- Randall, P, Burkhard, SSJ & Kutcher, J 1990, 'Exterior space for patients with Alzheimer's disease and related disorders', *The American Journal of Alzheimer's Disease and Related Disorders and Research*, vol. 5, no. 4, pp. 31-37.
- Willcocks, D, Peace, S & Kellaher, L 1988, *Private lives in public places: a research-based critique of residential life in local authority old people's homes*, Tavistock Publications, London.

Chapter 6: Care Delivery on Karibu Ward: Practicalities & Priorities

- Chapman, A & Kerr, D 1995, *Person-centred approach to care*, Dementia Services Development Centre, University of Stirling, Scotland.
- Cox, S, Gilhooly, M & McLennon, J 1997, *Dying and dementia*, Dementia Services Development Centre, University of Stirling, Scotland.
- Holden, U & Woods, RT 1995, *Positive approach to dementia care*, 3rd edn, Churchill Livingstone, Edinburgh.
- Jacques, A & Jackson, GA 2000, *Understanding dementia*, 3rd edn, Churchill Livingstone, Edinburgh.
- Jenkins, DAL 1998, *Intimate caring skills: bathing people with dementia: the bathroom and beyond*, Dementia Services Development Centre, University of Stirling, Scotland.
- Jenkins, DAL 1999, *Intimate caring skills: urinary and faecal incontinence: a heightened problem when dementia is a factor*, Dementia Services Development Centre, University of Stirling, Scotland.
- Molony, SL, Waszynski, CM & Lyder, CH 1999, *Gerontological nursing: an advanced practice approach*, Appleton & Lange.
- Norman, IJ 1999, 'Person-centred dementia care', in SJ Redfern & FM Ross (eds.), *Nursing older people*, 3rd edn, Churchill Livingstone, Edinburgh.
- Norman, IJ & Redfern, SJ (eds.) 1997, *Mental health care for elderly people*, Churchill Livingstone, New York.
- Packer, T 2000, 'Personal care and hygiene', in S Benson (ed.), *The care assistant's guide to working with people with dementia*, 3rd edn, Hawker Publications, London.
- Pearson, A, Vaughan, B & Fitzgerald, M 1997, *Nursing models for practice*, Butterworth Heinemann, Oxford.

- Pearson, A, Vaughan, B & Fitzgerald, M 1998, *Nursing models for practice*, 2nd edn, Butterworth Heinemann, Oxford.
- Shamy, E & Harrison, A (eds.) 1993, *Spiritual needs of people with dementia*, Dementia Services Development Centre, University of Stirling, Scotland.

Chapter 7: The Impact of Routine & Environmental Influences on Care Delivery

- Annerstedt, L, Fournier, K, Gustafson, L, Hallen, U, Malmkvist, I, Solo, S, Schult, J, Styernfeldt, G, Ahland, O & Tennek, J 1993, *Group living for people with dementia*, Dementia Services Development Centre, University of Stirling, Scotland.
- Archibald, C 1997, *Specialist dementia units: a practice guide for staff*, Dementia Services Development Centre, University of Stirling, Scotland.
- Beauchamp, TL & Childress, JF 1994, *Principles of biomedical ethics*, 4th edn, Oxford University Press, New York.
- Beth, A & Stokes, G 1999, 'Coping with professional care', in Stokes, G & Goudie, F (eds.), *Working with dementia*, Winston Press, Oxon.
- Chester, R & Bender, M 1999, *Understanding dementia: the man with the worried eyes*, Jessica Kingsley Publications, London.
- Genshy, O & Miller, GA 1970, *The sociology of organizations*, The Free Press, New York.
- Goldsmith, M 1996, *Hearing the voice of people with dementia: opportunities and obstacles*, Jessica Kingsley Publishers, London.
- Handy, CB 1981, *Understanding organizations*, Penguin Books, New York.
- Heath, H & Schofield, I 1999, *Healthy ageing: nursing older people*, Mosby, Italy.
- Klein, J 1969, *The study of groups*, Routledge & Kegan Paul, London.
- Molony, SL, Waszynski, CM & Lyder, CH 1999, *Gerontological nursing: an advanced practice approach*, Appleton & Lange.
- Moniz-Cook, E & Silver, M 1997, 'Residential care for older people: job satisfaction and psychological health in care staff', *Health and Social Care in the Community*, vol. 5, no. 2, pp. 124-133.
- Rader, J & Tornquist, EM (eds.) 1995, *Individualised dementia care: creative, compassionate approaches*, Springer Publishing Company, New York.
- Royal College of Nursing 1993, *The value and skills of nurses working with older people*, Royal College of Nursing, London.
- Scott, WR 1995, *Institutions and organizations*, Sage Publications, Thousand Oaks.

Toffler, A 1997, *Future shock*, Pan Books, London.

Wilson-Barnett, J 1983, *Nursing research: ten studies in patient care*, John Wiley & Sons, Chichester.

Chapter 8: Prioritising Patient Care

Allan, K 1994, *Wandering*, Dementia Services Development Centre, University of Stirling, Scotland.

Chapman, A & Kerr, D 1995, *Person-centred approach to care*, Dementia Services Development Centre, University of Stirling, Scotland.

Chester, R & Bender, M 1999, *Understanding dementia: the man with the worried eyes*, Jessica Kingsley Publishers, London.

Elgar, J & Marshall, M 1998, *Dementia: a practice guide for registration and inspection staff*, Dementia Services Development Centre, University of Stirling, Scotland.

Evers, J 1981, 'Tender loving care?: patients and nurses in geriatric wards', in L Archer Copp (ed.), *Care of the ageing*, Churchill, Livingstone, Edinburgh.

Hughes, B & Wilkin, D 1987, 'Physical care and quality of life in residential homes', *Ageing and Society*, vol. 7, no. 4, p. 414.

Jenkins, DAL 1999, *Intimate caring skills: urinary and faecal incontinence: a heightened problem when dementia is a factor*, Dementia Services Development Centre, University of Stirling, Scotland.

Kitwood, T 1997, *Dementia reconsidered: the person comes first*, Open University Press, Buckingham.

MacDonald, C & Teven, T 1997, *Who's in control?*, Dementia Services Development Centre, University of Stirling, Scotland.

Parker, J & Penhale, B 1998, *Forgotten people: positive approaches to dementia care*, Ashgate, Aldershor.

Rader, J & Tornquist, EM (eds.) 1995, *Individualised dementia care: creative, compassionate approaches*, Springer Publishing Company, New York.

Redfern, SJ & Ross, FM (eds.) 1999, *Nursing older people*, 3rd edn, Churchill Livingstone, Edinburgh.

World Health Organisation (WHO) 1986, *Dementia in later life: research and action. Report to WHO scientific group on senile dementia*, WHO Technical Report Series 730, World Health Organisation, Geneva.

Chapter 9: How Carers Managed Psychosocial Aspects & Special Challenges in Care Delivery

- Ashworth, P 1998, *Care to communicate*, The Whitefriars Press, London.
- Barnett, E 1997, 'Listening to people with dementia and their carers', in M Marshall (ed.), *State of the art in dementia care*, Centre for Policy and Ageing, London.
- Bloor, M, McKeganey, N & Fonkert, D 1988, *One foot in Eden: a sociological study of the range of therapeutic community practice*, Routledge, London.
- Chapman, A, Jackson, GA & McDonald, C 1999, *What behaviour? Whose problem? A guide to responding to the behaviour and aggression of people with dementia for staff working in nursing homes and residential care homes*, Dementia Services Development Centre, University of Stirling, Scotland.
- Cormack, D (ed.) 1985, *Geriatric nursing: a conceptual approach*, Blackwell Scientific Publications, Oxford.
- Froggat, A & Moffitt, L 1997, 'Spiritual needs and religious practice in dementia care'. In M Marshall (ed.), *State of the art in dementia care*, Centre for Policy on Ageing, London.
- Goldsmith, M, Kindred, M, Innes, A & Chapman, A (eds.) 1997, *Hearing the voice of people with dementia: a study guide*, Dementia Services Development Centre, University of Stirling, Scotland.
- Goudie, F 1999, 'Depression in dementia', in G Stokes & F Goudie (eds.), *Working with dementia*, Winslow Press, Oxon.
- Holden, U & Chapman, A 1994, *"Wait a minute", a practice guide on challenging behaviour and aggression for staff working with individuals who have dementia*, Dementia Services Development Centre, University of Stirling, Scotland.
- Hughes, C 1999, 'Depression in old age', in Redfern, SJ & Ross, FM (eds.), *Nursing older people*, 3rd edn, Churchill Livingstone, Edinburgh.
- Johnson, B 1996, 'Grief, loss and care of people who are dying', in SJ Redfern & FM Ross (eds.), *Nursing older people*, 3rd edn, Churchill Livingstone, Edinburgh.
- Keegan, C 1998, *Talking with Jean*, Dementia Services Development Centre, University of Stirling, Scotland.
- Kitwood, T, Buckland, S & Petrie, T 1995, *Brighter futures*, Anchor Housing, Oxford.
- Le May, AC 1999, 'Communication challenges in old age', in SJ Redfern & FM Ross (eds.), *Nursing older people*, 3rd edn, Churchill Livingstone, Edinburgh.
- Marr, J & Kershaw, B (eds.) 1998, *Caring for older people: developing specialist practice*, Arnold, London.
- Marshall, M 1997, *State of the art in dementia care*, Centre for Policy on Ageing, London.

- McKenzie, GJ 1985, 'Death and dying', in DFS McCormack (ed.), *Geriatric nursing: a conceptual approach*, Blackwell Scientific Publications, Oxford.
- Nolan, M 1996, 'The abuse of care: the relationship between the person and the place', in R Clough (ed.), *The abuse of care in residential institutions*, Whiting & Birch, London.
- O'Neill, PA 2002, *Caring for older adults: a health promotion perspective*, WB Saunders Company, Philadelphia.
- Pearson, A, Vaughan, B & Fitzgerald, M 1996, *Nursing models for practice*, 2nd edn, Butterworth Heinemann, Oxford.
- Rader, J & Tornquist, EM (eds.) 1995, *Individualised dementia care: creative and compassionate approaches*, Springer Publishing Company, New York.
- Redfern, SJ & Ross, FM (eds.) 1999, *Nursing older people*, 3rd edn, Churchill Livingstone, Edinburgh.
- Rogers, C 1967, *A therapist's view of psychotherapy: on becoming a person*, Constable, London.
- Shamy, E & Harrison, A (ed.) 1993, *Spiritual needs of people with dementia*, Dementia Services Development Centre, University of Stirling, Scotland.
- Stokes, G & Goudie, F (eds.) 1999, *Working with dementia*, Winslow Press, Oxon.
- Wagner, AW, Terri, L & Orr-Rainey, N 1995, 'Behavior problems among dementia residents in special care units: changes over time', *Journal of American Geriatrics Society*, vol. 43, no. 7, pp. 784-784.
- Whitley, JS 1992, 'The therapeutic community', in SR Baron & JD Haldane (eds.), *Community, Normality and Difference*, Aberdeen University Press, Aberdeen.

Chapter 10: Quality Care & Carers' Job Satisfaction

- Alfredson, BB & Annerstedt, L 1994, 'Staff attitudes and job satisfaction in the care of demented elderly people: group living compared with long-term institutions', *Journal of Advanced Nursing*, vol. 20, pp. 964-974.
- Astrom, SN, Nilsson, M, Norberg, A, Sandman, P & Winbald, B 1991, 'Staff burnout in dementia care relations to empathy and attitudes', *International Journal of Nursing Studies*, vol. 28, no. 1, pp. 65-75.
- Duxbury, ML, Armstrong, GM, Drew, DJ & Henley, SJ 1984, 'Head nurse leadership style with staff nurse burnout and job satisfaction in neonatal intensive care units', *Nursing Research*, vol. 33, pp. 97-101.

- Gilloran, AJ, McKinley, A, McKlew, T, McKee, K & Robertson, A 1994, 'Staff nurses' work satisfaction in psychogeriatric wards', *Journal of Advanced Nursing*, vol. 20, pp. 997-1003.
- Gilloran, AJ, McKlew, T, McKee, Robertson, A & Wright, D 1993, 'Measuring the quality of care in psychogeriatric wards', *Journal of Advanced Nursing*, vol. 18, no. 2, pp. 269-275.
- Gilloran, AJ, et al. 1995, 'Improving work satisfaction amongst nursing staff and quality of care for elderly patients with dementia: some policy implications', *Ageing and Society*, vol. 15, pp. 375-391.
- Humphris, GM & Turner, A 1989, 'Job satisfaction and attitudes of nursing staff on a unit for the elderly severely mentally infirm, with change of location', *Journal of Advanced Nursing*, vol. 14, pp. 298-307.
- Philip, I, Mutch, WJ, Ballinger, BR & Boyd, L 1991, 'A comparison of care in private nursing home, geriatric and psychogeriatric hospitals', *International Journal of Geriatric Psychiatry*, vol. 6, pp. 253-258.
- Procter, S 1989, 'The functioning of nursing routines in the management of a transient workforce', *Journal of Advanced Nursing*, vol. 14, p. 187.
- Redfern, SJ & Ross, RM (eds.) 1999, *Nursing care: developing partnerships in practice*, Bailliere Tindall, London.
- Thompson, N 1995, *Age and dignity: working with older people*, Ashgate Publishing, Hants.

Chapter 11: Summary of Study

- Basting, AD 2003, 'Looking back from loss: views of the self in alzheimer's disease', *Journal of Ageing Studies*, vol. 17, pp. 87-99.
- Bradford Dementia Group 1996, *Dementia Care Mapping*, 8th edn, University of Bradford, Bradford.
- Cheston, R & Bender, M 2000, *Understanding dementia: the man with the worried eyes*, Jessica Kingsley Publishers, London.
- Cormack, DFS 1985, 'Reality orientation', in DFS Cormack, *Geriatric nursing: a conceptual approach*, Blackwell Scientific Publications, Oxford.
- Douglas, B 1997, 'Sir James McCusker Training Foundation: developing a dementia care consultancy service', in M Marshall (ed.), *State of the art in dementia care*, Centre for Policy on Ageing, London.
- Holden, U & Woods, RT 1995, *Positive approaches to dementia care*, 3rd edn, Churchill Livingstone, Edinburgh.

- Hughes, B & Wilkin, D 1987, 'Physical care and quality of life in residential homes', *Ageing and Society*, vol. 7, no. 4, p. 414.
- Keegan, C 1998, *Talking with Jean*, Dementia Services Development Centre, University of Stirling, Scotland.
- Kitwood, T 1997, *Dementia reconsidered: the person comes first*, Open University Press, Buckingham.
- Kontos, PC 2004, 'Ethnographic reflections on selfhood, embodiment and alzheimer's disease', *Ageing and Society*, vol. 24, pp. 827-849.
- Norman, IJ & Ross, FM (eds.) 1999, *Nursing older people*, 3rd edn, Churchill Livingstone, Edinburgh.
- Pearson, A, Vaughan, B & Fitzgerald, M 1997, *Nursing models for practice*, Butterworth Heinmann, Oxford.
- Rader, J & Tornquist, EM (eds.) 1995, *Individualized dementia care: creative, compassionate approaches*, Springer Publishing Company, New York.
- Wilson-Barnett, J 1983, *Nursing research: ten studies in patient care*, John Wiley & Sons, Chichester.